

INFECTED LIVES: A HEIDEGGERIAN PHENOMENOLOGICAL STUDY OF
YOUNG AFRICAN AMERICAN HUMAN IMMUNODEFICIENCY VIRUS-
POSITIVE WOMEN

By

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Abstract

Human Immunodeficiency Virus (HIV) infection continues to be a significant public health concern for women of color. In the United States, approximately 290,000 women are HIV infected. African American women are disproportionately affected. Although they account for 12% of women living in the United States, 64% of women diagnosed and living with HIV infection are African American.

A review of the literature reveals that there is little research exploring the experiences of young African American women living with HIV. Additionally, spirituality and self-care practices positively influence the lives of individuals living with HIV infection. Few studies have explored these concepts among young African American women. Thus little is known about how young African American HIV infected women live with HIV, how they perceive spirituality in the context of HIV, if they draw on spiritual practices to assist in the management of their disease, and little is known about their engagement in self-care practices.

The purpose of this study was to explore the experience of young African American HIV infected women, the meaning of spirituality in their lives, and how they engaged in self-care to manage their disease. Heideggerian Hermeneutic phenomenological methodology was used for data collection and analysis. One pattern, Infected Lives, and four themes, Living Alone with HIV, Living with Unresolved Conflicts, Living with Multiple Layers of Betrayal, and Living in the Everydayness of HIV were developed and interpreted from the stories shared. The pattern and themes portray the very complex and challenging experiences of young African American women living with HIV infection. They have felt alone and abandoned, betrayed and discriminated against in their interpersonal and

social systems. Facing a life-threatening illness, they were often dealing with conflicts of hope and anguish in the relationships with their children, being externally strong, but internally feeling fragile and vulnerable, and caring for themselves and caring for families. In the everydayness of living with HIV, they had to cope with unrelenting depression and other physical symptoms of HIV and/or medication therapy. In this everydayness, they engaged in self-care activities that included spiritual and family support, which provided strength to live with a chronic illness.

Nurses and other health care providers need to understand the everyday experiences of African American women living with HIV to assure holistic, culturally competent care. Depression and other mental health issues need to be addressed through culturally appropriate assessment and interventions. Through comprehensive education the public needs to be better informed about HIV/AIDS to eliminate stigmas related to this diagnosis. Health care policy should address health disparities experienced by this population. Further research is suggested, including the development of telephonic interventions designed to reduce depression and community based participatory research to develop culturally appropriate nursing interventions for attaining optimal health among this population.

Dedication

This dissertation is dedicated to the eleven beautiful young women who welcomed me into their homes and openly shared their experiences living with HIV – I cannot express my gratitude that you were so willing to share your stories with me; to my boyfriend, Forrest, who has believed in me every step of the way in this journey; to my family who have also cheered me on, from their homes in Atchison, Olathe, Chicago, and Hamburg; and lastly, to my Mom, who I know is sending me her love and support from Heaven.

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Chapter One: Background

The World Health Organization (1958, pg. 1) defines health as the “state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity”. A comprehensive understanding of young African American Human Immunodeficiency Virus (HIV)-infected women’s health has remained elusive, because how these women live with HIV-infection has not been extensively explored. To receive the diagnosis of HIV infection is often devastating. It is associated with a wide range of experiences including emotional distress, helplessness, low levels of self-esteem, internalized stigma that can result in guilt and self-blame, and uncertainty (Kylama, Vehviläinen-Julkunen, & Läderirta, 2001). The effect of HIV on all aspects of an individual’s life often precipitates a search for meaning and for ways to manage the disease (Woodard & Sowell, 2001). Despite the advances in the medical management of HIV infection, living with a chronic, incurable, and eventually fatal disease presents multiple challenges and has significant physiological, psychological, social, and spiritual implications.

Challenges are worsened when individuals have many stressors, such as poverty, that compete with their ability to fully engage in treatment regimens to manage their disease. Spirituality and health promoting self-care activities may assist individuals in managing their disease and may mediate the relationship between multiple stressors and disease outcomes. Spirituality has been linked to improved health outcomes (Morse, Morse, Klebba, et al., 2000). Numerous studies focusing on spirituality and illness support that spirituality and religious practices positively influence health promotion and coping with multiple stressors in the context of living with a chronic illness (Tuck,

McCain, & Elswick, 2001; Vance, 2001; Villagomez, 2006). The role of spirituality and religion in health-seeking behaviors may be of significance for nurses attempting to better understand the complex construct of health within a diverse population of individuals.

Within the construct of physical health, African Americans have increased rates of chronic illness and higher death rates as compared to Caucasians (Dessio, Chao, Kronenberg, et al., 2004). Spirituality and religion have traditionally been strong tenets of African American culture and have been a healthcare resource in African American communities, as a means of addressing health care needs that have not been met through traditional health care settings (Dessio, Chao, Kronenberg, et al., 2004). Further, in studies of HIV-infected women, spirituality has helped define their lives as being meaningful, thus prompting them to engage in health promoting activities that support quality of life, while living with an incurable, chronic disease (Sowell, Moneyham, Hennessy, et al., 2000; Tuck, McCain, & Elswick, 2001). Although most women were spiritual prior to the diagnosis of HIV, their spirituality often changed. Thus exploring spirituality among young HIV-infected African American women is important to better understand how they address health concerns.

As the financial burden of chronic disease continues to increase, health care providers are re-evaluating the delivery of health care, with an increasing emphasis on health promotion. The responsibility for health is beginning to shift from health care providers to the healthcare consumers (Callaghan, 2003). Consumers must acquire and maintain capabilities to perform self-care behaviors that promote health. Self-care behaviors have been linked to improving outcomes among individuals with chronic disease (Vance, 2001; Villagamoza, 2008), improving quality of life and decreasing

medical costs (Tufts, Wessell, & Kearney, 2010). Multiple researchers have evaluated self-care behaviors among HIV-infected individuals to manage their disease (Tufts, Wessell, & Kearney, 2010). Such practices among HIV-infected women have included health promotion, taking responsibility for one's health, and illness management. Understanding how young African American HIV-infected women engage in self-care practices is necessary for nurses to support health promotion among this group of women.

Significance of the Problem

HIV infection continues to be a significant public health concern and increasingly so among women, particularly for women of color. Globally, women now account for nearly half of the 33.3 million persons living with HIV-infection (UNAIDS, 2010). In the United States, 27% of new HIV infections occur in females (Centers for Disease Prevention and Control, 2008a) compared to 8% in 1985 (KFF, 2012a). African Americans have been disproportionately impacted by HIV-infection and the disparity continues to grow, particularly among African American women. Although they only account for 12% of the population of women living in the United States, 64% of women diagnosed and living with HIV infection are African Americans. The Kaiser Family Foundation reports that more than six in ten new HIV infections in African American women were among females between the ages of 13 and 39 and over one-third were among those between the ages of 13 and 29. The impact of HIV and AIDS on young black women has significant implications at the individual, family, community, and population levels. Despite the successes in HIV and AIDS treatment, this preventable disease was the third leading cause of death among African American females between the ages of 25 and 44 in 2007 (KFF, 2012a) and is in the top ten leading causes of death

for African American females ages 10 to 54 (Centers for Disease Control and Prevention, 2011).

Complex social and contextual factors, including the triple oppression of sexism, racism/discrimination, and classism, have negatively influenced the risk for and the disease trajectory of HIV infection among ethnic and racial minority women. The construction of at risk groups in the landscape of HIV-infection has provoked the AIDS crisis by 1) misunderstandings of who is and is not at risk; 2) stigmatizing and marginalizing individuals with AIDS; 3) poor targeting of educational interventions; and 4) concentrating on the disease of AIDS without noting the proliferation of unemployment and structural poverty, the informal economy of drugs, the lack of primary and preventive health care available, and the oppression of women and individuals of color (Schiller, 1992). As such, a public voice has been absent amongst this group of women, thereby exposing the tragic nature of HIV infection on this vulnerable population. “Women of color are easily the least visible among AIDS patients and, it can be remarked, the only group with no ‘celebrity’ victims with which to highlight a claim to attention” (Reid, 2000, pg. 715). African American women, in view of the increasing incidence and prevalence of HIV infection within this group, are a vulnerable population without a strong voice.

Within the context of population-based health care, drawing upon the important public health nursing concepts of social justice and care of vulnerable populations, population-based health nurses are in a key position to advocate for and provide holistic care to young African American HIV-infected women. Despite the emphasis in the discipline of nursing to provide skilled and technologically focused care, nurses

recognize the importance of spiritual care provided to clients (Woodard & Sowell, 2001). Additionally, given the substantial body of literature within nursing exploring self-care behaviors and illness (Tufts, Wessell, & Kearney, 2010), nurses recognize the importance of self-care behaviors in the management of disease for improved outcomes. There has been little research that has solely focused on young African American women living with HIV infection. Therefore, holistic and culturally appropriate interventions in population-based nursing, drawing upon concepts of spirituality and health promoting self-care behaviors, have been lacking. Such key concepts, which have been linked to improved health, and targeting this population of women, need to be further explored.

Two of the overarching goals of Healthy People 2020 are to promote quality, longer lives free of preventable disease, disability, and premature death and achieve health equity, eliminate disparities, and improve the health of all groups (U.S. Department of Health and Human Service, 2009). Several initiatives related to HIV infection support these overarching Healthy People 2020 goals, specifically HP2020 – 7: Reduce deaths from HIV infection; HP2020 – 9: Increase the proportion of persons surviving more than three years after a diagnosis with AIDS; and HP2020 - 15: Increase the percentage of HIV-infected adolescents and adults who receive HIV care and treatment consistent with current standards. Interventions developed and tested by population-based health nurses that promote holistic self-care practices may increase longevity and quality of life among young HIV-infected African American women. However, such interventions cannot be developed without better understanding how African American women live with HIV-infection.

Significance for Nursing Research

Research evaluating self-care practices utilized by HIV-infected women suggests that physical, mental, and spiritual self-care endeavors are essential for holistic self care (Peltzer & Leenerts, 2007). Further, research evaluating self-care practices among HIV-infected women supports spirituality as a vital component of coping with the disease, particularly among minority women (Gant & Welch, 2004; Moneyham, Hennessy, et al., Plach, Stevens, & Keigher, 2005). Although there are studies that evaluate spirituality in the context of self-care activities and being a mother while living with HIV infection, there have not been any studies that have explored the totality of living with HIV as a young African American woman, or the meaning of spirituality and integration of self-care activities. Understanding the experiences of living with an incurable disease and the extent to which spirituality and self-care practices are important components of these women's lives is necessary for the development of comprehensive holistic and culturally appropriate population based and acute care nursing interventions that support the Healthy People 2020 initiatives addressing HIV infection.

Abrums (2000) posits that the relationship between macro-social levels, intermediate levels, and the individual level in health and healing can best be understood through an examination of health care systems, the daily lives of individuals involved in a phenomenon of health or illness, and by listening to the perspectives of the people that experience oppression within their world. The relationships between macro-social levels, intermediate levels, and the individual level in health and healing are inter-relational. These relationships in the context of HIV infection among young African American

females can only be understood by first examining the everydayness of their lives while experiencing this disease.

Heideggerian Hermeneutic Phenomenology seeks to understand the meaning of the lived experience of individuals. Therefore, Heideggerian phenomenological methodology was appropriate to use to attempt to understand the lived experiences of HIV infection among young African American women, and to understand the meaning of spirituality and self-care practices within the everydayness of their lives.

Aims and Research Question

The specific aims of the study were to understand the lived experience of being a HIV infected young African American woman, understand how HIV infected young African American women define spirituality and if they incorporate spirituality into their everyday lives while living with HIV infection, and understand how HIV infected young African American women define and practice self-care in the context of living with HIV-infection. The three specific research questions posed in this research study were 1) What is the lived experience of being a young African American HIV infected woman, 2) How do young African American women living with HIV infection define the meaning of spirituality in the lived experience of being HIV-infected, and 3) How do young African American women living with HIV infection define and practice self-care behaviors in the context of HIV infection? The overall goal was to understand the meanings of the experiences shared in the narratives. This is important for future development of holistic, culturally appropriate nursing interventions that will optimize young African American HIV-positive women's overall health to achieve the Healthy

2020 goals of quality and longevity of life and achieving health equity and reducing health disparities.

Chapter Two: Review of the Literature

The purpose of this review was to examine the current literature relevant to the study. First, an overview of the epidemiology of HIV infection, including incidence and prevalence, morbidity and mortality, and medication adherence among African American women was presented. The purpose of the review of literature related to the epidemiology of HIV infection among African American women was to set the stage for why studying this population is so important. Second, social and contextual factors that influence African American women living with HIV infection were reviewed. The purpose of this literature review was to understand the context of living with HIV infection for African American women. Lastly, an analysis of self-care behaviors and spirituality in the realm of nursing care and in the context of HIV infection among African American women was discussed. A comprehensive review of the literature from 2000 – 2012 was conducted through Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Google Scholar, using CINAHL Headings, Medical Subject Headings terms, and generic terms that included HIV, African American, Women, Females, Medication Adherence, Patient Compliance, Gender, Violence, Health Policy, Spirituality, and Self-Care.

Epidemiology of HIV Infection among African American Females

Approximately 1.2 million individuals in the United States are currently living with HIV/AIDS, of which at least 290,000 are women (KFF, 2012). The Centers for Disease Control and Prevention (CDC) suggests that at some point in her lifetime, one in 32 African American women will be diagnosed with HIV, compared to one in 106 Latina women and one in 526 Caucasian women (CDC, 2011). A group increasingly affected

by HIV and AIDS are females between the ages of 18 and 44 (Edwards, 2006). More than six in ten new cases of HIV infection in 2009 were among women ages 13 to 39, including African Americans, Caucasians, and Latinas (KFF, 2012). Medical management of HIV may be more difficult for young African American females, thereby influencing morbidity and mortality rates. Multiple factors influence HIV and AIDS morbidity and mortality rates, including delayed access to health care thereby leading to delayed diagnosis and commencement of treatment modalities; poverty (Cousar, 2005); psychosocial trauma (Mugavero, Wells Pence, Whetten, et al., 2007), such as histories of violence; and low adherence rates to antiretroviral therapy (Feaster, Brincke, & Mitrani, 2010). Histories of abuse and limited access to health care will be discussed later in the review of the literature.

Antiretroviral Therapy

The objectives of antiretroviral therapy (ART) are to reduce the concentration of the viral load and to maintain it at an undetectable level to slow the progression of HIV infection, thereby improving morbidity and mortality rates (Edwards, 2006; Feaster, Brincks, Mitrani, et al., 2010; Meade, Hansen, Kochman, & Sikkema, 2009; Mugavero, Wells Pence, Whetten, et al., 2007), and quality of life for individuals living with the disease (Ramirez Garcia & Cote, 2003). Low adherence results in treatment failure, with the development of viral mutations, resistance to therapies (Edwards, 2006; Gracia Jones, 2003) and exacerbation of symptoms (Abel & Painter, 2003; Edwards, 2006). Adherence to medication therapy is not only optimal but necessary for individuals to achieve longevity and quality of life in the context of living with HIV infection and AIDS.

From a public health perspective, when individuals do not adhere to their treatment regimens, there is the potential for increased rates of transmission of the virus (Edwards, 2006), including medication-resistant HIV strains (Feaster, Brinks, Mitrani et al, 2006). However, sustained adherence can promote a challenge to individuals, as therapies are often complex, pose life-style restrictions, and have adverse side effects (Abel & Painter, 2003; Mills, Nachega, Buchan, et al., 2006). In a meta-analysis of treatment adherence, only 55% of individuals in North America adhered to medication regimens at least 80% of the time, with 95% medication adherence as optimal (Mills, Nachega, Buchan, et al., 2006). Medication adherence is an important component in the management of HIV infection.

There are racial disparities in ART therapy and adherence. In a recent study, researchers explored 1,327 patients' trust in physicians and racial disparities in HIV care (Saha, Jacobs, Moore, & Beach, 2010). Most (N= 1,104) of the participants were African American and 201 were Caucasian. Researchers evaluated the level of trust in health care providers, duration in care, receiving ART, and achieving viral suppression. They also assessed if there were correlations between trust and receiving ART or achieving viral suppression. African Americans reported lower levels of trust in providers than did Caucasians. They were also less likely to be on ART, to adhere to medication therapy, and to achieve viral suppression. When there was complete trust in providers, disparities in care remained; however trust was associated with ART adherence. The findings suggest that developing trusting relationships is important to reducing disparities in ART adherence, which can lead to long-term survival.

Women are less likely to adhere to anti-retroviral medication therapy than are men. In a recent study evaluating factors influencing medication adherence among 2,791 HIV-infected women in six U.S. cities, researchers found that women reporting childcare burden, living in households without other adults, and not receiving social services assistance were more likely to report low adherence to treatment therapies (Merenstein, Schneider, Cox, et al., 2009).

In a qualitative study examining HIV-infected women and health care providers' perceptions of factors associated with medication adherence, patient participants identified emotional trauma associated with the diagnosis and treatment of HIV/AIDS, stigma, side effects of medication therapy, and changes in medication therapy as hindering their adherence to ART (Abel & Painter, 2003). Poverty, lack of social support, and lack of social services may hinder medication adherence, which then affects longevity and quality of life. Few studies have been conducted to examine medication adherence and factors that influence medication adherence among HIV infected African American women.

Gant and Welch (2004) interviewed thirty African American women to evaluate barriers and facilitators to medication adherence. Although over half of the participants reported 100% adherence to medication regimens, almost 50% of the participants reported medication adherence rates less than the recommended 95% adherence rate for optimal viral suppression. The participants reported that facilitators to medication adherence were simplicity of medication regimen, having children, encouragement from health care providers, support groups, medication assistance programs, and the ability to obtain refills at methadone maintenance treatment programs. Barriers to medication

adherence were identified as complex medication treatments, including complexity of regimen, number of pills, and difficulty keeping track, medication perceived as a negative reminder of infection, side effects of the medications, and feeling well, thus believing that it was unnecessary to continue medication therapy.

Edwards (2004) conducted a qualitative study to evaluate the relationship between perceived social support and medication adherence among African American HIV-infected women. Facilitators of medication adherence included having a supportive family and presence of young children in their lives. Common themes of barriers to medication adherence were HIV related stigma, feeling unloved, relationship turbulence, and being married to an HIV infected partner. For many of the women, there were negative consequences of being enmeshed in relationships in which the stigma of HIV infection inhibited them from being engaged in medication adherence. For them, rather than going “public” and risk social isolation of disclosing their HIV status, they opted to forgo medication. Women who felt supported and cared for were more likely to be adherent, as were women with children, which contrasts to the previous study on childcare and medication adherence, but matched Gant and Welch’s findings.

These studies again support that medication adherence is a complex issue, influenced by many everyday factors within the lives of African American HIV-infected women. Understanding how women live with HIV-infection will allow population-based nurses, other health care providers, and researchers to evaluate medication treatment programs and implement holistic interventions that ensure optimal adherence to support improved morbidity and mortality rates and quality of life.

Cultural and Social Contextualization of HIV for African American Women

The literature exploring the lives of HIV-infected women often displays a bleak picture. Social isolation, stigma, and disparities in access to healthcare resources influence the disease trajectory (Peltzer & Leenerts, 2007), as well as racism and discrimination, gender power differentials, histories of abuse, and poverty. Such social and cultural factors have negatively influenced the disease trajectory of individuals of color, particularly women, who remain the most vulnerable of people living with HIV. Gender, including sexuality and inter-relational violence, race, including discrimination and mistrust of the health care system, and social structures, including poverty and health care disparities, are examined. Gender, race, and classism are important to further examine because they are elements of personal identities which are structurally embedded, simultaneous, and overlapping (Watkins-Hayes, 2008) and the intersection of gender, race, and class has continued to marginalize African American women, increasing their vulnerability to health threats and disparities (Shambley-Ebron & Boyle, 2004). Because factors related to sexism, racism, and classism are embedded constructs within the everydayness of many African American women, they are important to address within the review of the literature.

Gender, Sexuality, and Violence

Multiple gender factors influence HIV-infected African American women's disease trajectory. CDC officials suggested that one of the most critical issues in the context of HIV and AIDS is the status of women. Inferior social and legal rights, imbalanced power differentials in sexual relationships, and the burden of being caregivers within family units result in a social vulnerability among women to HIV infection

(Woodard, 2001). Rae Jenkins (2000) states that gender role socialization and sexual relationships influence HIV transmission and post-infection survival for women of all ethnicities and social classes, as such variables increase vulnerability to HIV infection and the ability to attend to health after the diagnosis of HIV had been made. Simply being a female negatively influences women's ability to negotiate safer sexual practices; to be a poor female further instigates a social environment in which women are vulnerable to sexually transmitted infections, as they may use sexual relationships for survival, further increasing their risk. They may not attend to their health once becoming infected due to financial constraints.

Historically, one function of women's sexual relationships has been to ensure economic resources as a solution to structural disadvantage. Disconnecting from these sexual relationships may diminish their ability to ensure economic resources. This may disadvantage women in their sexual relationships, decreasing their power differential to ensure safe sex, as they may tolerate power imbalances within the relationship to ensure economic stability (Reid, 2000). In relationships in which men have been dominant, women have had decreased sexual self-efficacy, and decreased sexual decision-making abilities, compared to women who equally share power (Rae Jenkins, 2000).

Within the context of gender, histories of violence are a common aspect of living with HIV infection. There is a high prevalence of abuse amongst women living with HIV and AIDS (Gant & Welch, 2004; Leenerts, 2003; Maman, Campbell, Sweat, et al, 2000). Researchers postulate that women at the highest risk for intimate partner violence have similar demographic characteristics as women who are HIV-infected, such as a history of childhood abuse, substance abuse histories, and high risk taking behaviors (Cohen,

Deamant, Barkan, et al, 2000). Maman, Campbell, Sweat, and Gielen reviewed the literature to examine the relationship between intimate partner violence and HIV infection (2000). They posit that sexual violence, women's limitations in negotiating safe sexual practices, and childhood physical and sexual abuse leading to later sexual risk-taking behaviors, were factors that increased women's risk for HIV infection, disclosure of the diagnosis of HIV infection further provoked situations of violence.

Histories of abuse, including childhood sexual abuse and intimate partner violence, have been examined as factors that influence the transmission of HIV infection among African American women (Fuentes, 2008; Laughon, Gielen, Campbell, et al., 2007). Histories of abuse have been examined secondarily in several studies of women living with HIV infection. However abuse histories have not been a key concept identified in most research studies as to how they may shape the lives of women living with HIV infection. Further, researchers exploring self-care behaviors among Caucasian HIV-positive women have found that histories of abuse leave women disconnected from their own self-care because they have not learned how to care for themselves both physically and psychologically (Leenerts, 1999). The complex interplay of sexual and physical abuse may precipitate an environment in which women are ill-prepared to engage in health-promoting self-care practices, including holistic management of their disease (Hurst, Montgomery, Davis, et al., 2005).

Race, Discrimination, and Mistrust in the Health Care System

Residential segregation, past and current discrimination, and limited economic resources perpetuate untreated health problems among the most vulnerable of individuals (Watkins-Hayes, 2008), including African American women. Woodard (2002) states that

discrimination cannot be disregarded as the majority of HIV-infected women are African American. Covert racism is unfortunately a common experience for African Americans, permeating social institutions and thereby increasing racial inequality in education, employment, and justice (Trepagnier, 2006). African American women continue to suggest that they are not understood or embraced by mainstream White America, resulting in a fragmentation in how they live their lives and increasing everyday stress and depression rates that negatively influence their health (Jones & Shorter-Gooden, 2003). Discrimination overtly influences African Americans' experiences when they enter the health care system.

Significant historical events that have been blatantly racist, such as the Tuskegee Syphilis Study, have diminished the trust among African Americans in the health care system. The purpose of the Tuskegee Study, a prospective longitudinal study, was to evaluate the course of syphilis. During the study, penicillin was identified as a medical cure for syphilis. Despite this new information, the CDC researchers neglected to inform the subjects, nor treat them with penicillin. This experiment "has come to symbolize racism in medicine, misconduct in human research, the arrogance of physicians, and government abuse of black people" (Abrums, 2000, pg. 91). The Tuskegee experiment should not be viewed as an isolated event, rather another event in the setting of mistrust, as viewed by African Americans. "The powerful legacy of the Tuskegee Study endures, in part, because of the racism and disrespect for black lives that it entailed, mirrors black peoples' contemporary experiences with the medical profession" (Abrums, 2000, pg. 90). The Tuskegee study is but one incidence that has prompted distrust among African Americans toward the health care system. Racism and discrimination perpetuates the

silencing of young African American HIV infected women, ignoring their everyday lives and often evoking a very negative portrayal of them, without taking into account the bleak setting of a life of poverty and despair that many of these women face.

Class, Poverty, and Access to Healthcare

Women living in poverty, and particularly women of color, have worse health outcomes than the majority of women living in the United States (Reid, 2000). Women who are HIV infected are disproportionately poor (National Alliance of State & Territorial AIDS Directors, 2008; Tuan, 2006), particularly African American women (Vyavaharkar, Moneyham, & Corwin, 2008). Approximately 77% of all HIV-infected women living in the United States have an annual income less than \$10,000 (Gant & Welch, 2004). Poverty, interfacing with poor health, isolation, discrimination, and histories of violence, often predates infection with HIV (Gilbert, 2003). In 2003, 22 percent of families living in poverty were African American compared to ten percent of all families (National Alliance of State & Territorial Directors, 2008). Single-women households are five times more likely to be living in poverty as compared to two-parent households. In 2002, 43 percent of African American families were characterized as single-women led households (National Alliance of State & Territorial Directors, 2008; Tuan, 2006). Poverty often positions African American women in vulnerable situations, such as engaging in transactional sex for financial stability, that force them to negate their own health as they try to support their family (National Alliance of State & Territorial Directors, 2008). Gilbert states that African American HIV-positive women “exist and adapt to survival in environments where situational risks for HIV and other social ills are pervasive” (2003, pg. 8).

Complicating the lives of women living with HIV infection is the inaccessibility of health care services. The National Alliance of State and Territorial AIDS Directors (2008) posit that several factors negatively influence HIV-positive African American women healthcare needs at the primary, secondary, and tertiary levels, including lack of access to health care and treatment services, limitations in public programs, lack of coordination between primary and specialty providers, low cultural competency among providers, and lack of socio-cultural understanding of African American females. Vyavaharkar, Moneyham, and Corwin (2008) suggest that African American HIV-infected women have difficulties in accessing care leading to episodic and fragmented care. Such factors may negatively influence the disease trajectory, increasing morbidity and mortality rates among this population.

In summary, the constructs of sexism, racism, and classism, particularly abuse histories, poverty, and healthcare disparities, appear to negatively influence African American women's risk for HIV infection and its disease trajectory. What is not completely understood is how African American HIV-infected women deal with these social factors in their everyday lives and if such factors influence their lives and impact their ability to take care of themselves.

Self-Care Behaviors

Self-care behaviors encompass a wide range of activities utilized by individuals within the continuum of health and illness. For the purpose of the literature review, definitions of self-care behaviors and health promoting activities are provided. Orem defines self-care behaviors as the practice of activities among mature persons on their own behalf to maintain life and well-being (Orem, 1991). Health promotion is the effect

of multiple systems on health outcomes, with the understanding of human potential for change at the individual level, motivated by desire to increase the level of health in the presence or absence of health (Pender, Murdaugh, & Parsons, 2006). Self-care behaviors in the literature specific to HIV individuals have been defined as self-described, self-initiated behaviors that women use to promote and improve their health. They include seeking information, communication with health care professionals, adherence to medication therapies, drawing upon social support systems, diet, exercise, and practicing spirituality and religion (Tufts, Wessell, & Kearney, 2010).

Self-Care Behaviors among African American HIV-Infected Women

Few researchers have examined self-care behaviors among African American HIV-infected women. Researchers evaluated the influence of certain basic conditioning factors (age, socio-cultural orientation, family system, and health state) on self-care agency and self care practices among 62 African American HIV-infected women (Hurst, Montgomery, Davis, et al., 2005). The authors found that the participants had economic, social, and health care disparities. Although there were not significant correlations between most of the basic conditioning factors and self-care agency and self-care practices, there were significant positive correlations between health state and self-care practices, suggesting that women who had increased reports of their health state had increased levels of self-care agency and greater levels of engagement in self-care practices. There were significant positive correlations between functional and social support between self-care agency and self-care behaviors, suggesting that social support systems increase women's self-care agency and ability to engage in self-care practices. Implications for healthcare providers include the development and support of

comprehensive social services in health care facilities and within the community to support HIV-infected individuals.

Shambley-Ebron and Boyle (2006) conducted a critical ethnographic study of ten African American HIV-infected mothers to explore their experiences, beliefs, values, and traditions, their self-care practices, and mothering experiences of HIV-infected children. The overarching theme was Creating a Life of Meaning, with sub-themes of Disabling Relationships, Strong Mothering, and Re-defining Self-Care. Within the domain of self-care practices, rather than follow the self-care practices prescribed by healthcare practitioners, such as nutrition, rest and exercise, and stress reduction, which the participants believed to be impractical in the setting of poverty and scarce resources, they redefined and incorporated creative, culturally consistent self-care practices, such as spirituality and religion, the act of being a mother, and family support. The authors state that greater insight into the cultural experiences and health practices of African American women may assist to reduce health disparities.

Tufts, Wessell, and Kearney (2010) explored self-care behaviors, and facilitators and barriers to self-care activities in a sample of 21 African American HIV-infected women. Two overarching themes about the meaning of self-care behaviors emerged: Me First, and Mind, Body, and Spirit. Within these themes, women described taking care of themselves as doing what the doctor says and living healthy. Participants described spirituality, social support and acceptance of the disease as facilitators to engaging in self-care behaviors. Barriers to self-care behaviors included caregiver responsibilities, stigma, nondisclosure, and negative attitudes, held by the participants or others. The

authors concluded that self-care behaviors were important goals for the participants in maintaining health.

Only three research studies were found in the literature exploring self-care behaviors of African American HIV-infected women. One study examined the relationship between certain basic conditioning factors, self-care agency and self-care behaviors (Hurst, Montgomery, Davis, et al., 2005). One study examined self-care behaviors of HIV infected mothers caring for their children (Shambley-Ebron & Boyle, 2006). Lastly, one explored self-care behaviors of women between the ages of 29 and 61, with a mean age of 43 years (Tufts, Wessell, & Kearney, 2010). Thus, the findings of this study could be influenced by the maturity of an older population of women living with HIV infection. Although nursing now has a better understanding of how African American HIV infected women care for themselves, none of the studies explored self-care health promoting behaviors among young African American women between the ages of 18 and 35 years, a group that may not have developed the maturity to fully engage in self-care health promoting behaviors, particularly in the context of living with an incurable disease.

Spirituality

There has been a lack of conceptual clarity when defining spirituality within the context of health and illness. To provide a construct of spirituality as a framework for the review of literature related to HIV infection, the conceptualization of spirituality for the researcher is provided. Stevens Barnum (2003) conceptualizes spirituality as an individual's search for, expression of, and connection to a meaningful and greater experience.

Spirituality among African American Women

Spirituality, under the umbrella of religion, has consistently played an important role in the lives of African Americans (Dessio, Chao, Kronenberg, et al., 2004; Prado, Feaster, Schwartz, et al., 2004), influencing virtually every facet of their lives (Gonnerman, Lutz, Yehieli, et al., 2008) including folk-healing practices and ability to cope with adversity (Mattis, 2000). Historically, African American churches have provided multiple services beyond a religious framework, including nurturing major voices during the Civil Rights movement and sustaining economic and social organizations that support African Americans (Dessio, Chao, Kronenberg, et al., 2004). Today, spirituality and religion continue to be valuable tenets in the lives of African Americans, supporting a refuge from racism within a larger sociological context, a key place of the formation and sustainability of social and political leadership, and to come together as a community of like-minded individuals (Jones & Shorter-Gooden, 2003). Spirituality and religion have influenced interpersonal relationships, civic responsibilities, and political beliefs (Mattis, 2000). The use of religious and faith activities mitigate the effects of mental and physical distress on African Americans (Mattis, 2000; Prado, Feaster, Schartz, et al., 2004) and the connection between religion and health may promote avoidance of negative health behaviors (Gonnerman, Lutz, Yehieli, et al., 2008). Health-seeking behaviors may be linked to spirituality and religion, particularly among African American women, as they are more spiritual and religious than African American men (Dessio, Chao, Kronenberg, et al., 2004). There are few studies that have focused on the concepts of spirituality and health among African American women.

Researchers examined spirituality, religion and the use of complementary and alternative medicine (CAM) among African American women (Dessio, Chao, Kronenberg, et al., 2004) and found that nearly half of the women used religion or spirituality for health reasons. African American women were more likely to use religion and/or spirituality more often than other ethnic/racial groups. Not only did African American women use religion and spirituality for conditions, such as cancer and heart disease, they turned to religion and spirituality for mental health conditions, such as depression. Additionally, African American women who used religion and spirituality for health reasons were more likely to see a health care practitioner and use CAM. However, there was an association of higher education and income with both religion and spirituality and CAM. This finding suggests that education and income allow access to CAM, which may be congruent with personal philosophies. Additionally such therapies may not be available to lower income African American women. The authors did not specifically address if CAM, including spirituality and religion replaced medication therapy, although they reported that some women who used CAM did so because they could not tolerate traditional medication therapy. The author concludes that religion and spirituality are associated with health-seeking behaviors among African American women and that further research is needed to better understand the causal relationships between religion and spirituality and disease outcomes.

Mattis evaluated the definitions of spirituality and religion among 128 African American women (2000). Content analysis evaluating women's written definitions of spirituality revealed 13 categories. The researcher analyzed the categories to evaluate the percentage of women who identified each category as a common concept of spirituality

and religion. The four most common themes coded and identified by the participants included a connection to or belief in a higher external power, consciousness of metaphysicality, understanding and being in touch with oneself, and life direction. The author suggests that the analysis of the participants' definitions of spirituality and religion is not in alignment with current literature which does not incorporate religiosity into definitions of spirituality and does not take into account beliefs about ancestors and other spirits, which were important to women in this study. As such, given the powerful importance of spirituality and religion in the lives of these African American women, healthcare practitioners need to be aware of this vital dimension in the complex construct life of African American women and how it is defined and enacted, particularly as it may influence health care practices.

Spirituality among African American HIV-Infected Women

The role of spirituality has been described as an important predictor of physical and mental well-being of individuals with HIV and AIDS (Coleman, Holzemer, Sanzero Eller, et al., 2006; Tuck, McCain, & Elswick, 2001). African American women and in particular HIV-seropositive women view traditional medical treatment as secondary to spirituality as influencing their survival (Woodard, 2002). Morse and colleagues examined the use of religion as a component of a longitudinal study of HIV-infected African American women and their uninfected children (2000). Using a matched sample of 104 HIV-infected women and 149 HIV-negative women, they compared religiosity, perceived physical health status, mental health status, high risk behaviors, and health status between the two groups. Assessing the public and private practices of religion, they found that there was a statistically significant difference in religious practices, with

HIV-infected women more often using private methods, such as prayer, and less likely to participate in public religiosity, such as attending church services. HIV-infected women who did participate in public religious practices were more likely to seek mental health care, had increased perceptions of physical health status, enhanced healthy lifestyle behaviors, increased perception of control over their health, and higher educational attainment. Public participation in religious activities may be a protective factor for HIV-positive women, keeping them both physically and mentally healthy. The social support garnered through public forms of religious activities and the regular reinforcement of spirituality provided through public religiosity could be viewed as assisting women to attain physical and mental strength and wellbeing. The authors suggest that not only should church organizations expand their outreach efforts to include individuals with HIV/AIDS, but health care professionals should partner with churches to provide preventive health services and through these relationships foster a caring atmosphere for individuals already infected with HIV/AIDS to support their overall health.

Woodard (2002) examined how thirteen African American HIV-infected women living in North Carolina defined spirituality and used spirituality to manage their disease through a grounded theory study. The author developed a model of spirituality, in which there were four components: private, public, practical, and profound. The second model that emerged from the data was a theory of Engaging Spirituality to Manage HIV. Two conditions: Learning about Spirituality and the Catalytic Event, being diagnosed with HIV infection, existed prior to the participants being able to engage in spirituality to manage HIV. After a period of time, they went through two stages of engaging in spirituality: Falling back on Faith and then Living the Engaged Life, in which they were

able to diminish feeling isolated, became empowered, and transcended the present. The theory is intended to explain how HIV-infected African American women use spirituality to manage their disease, linking the genesis of their spirituality to the use of spirituality during a crisis, to the various ways in which spirituality is used to manage a chronic disease, and the positive outcomes as a result. Implications for practitioners are to assess patients' spirituality, including spiritual mentors to whom they can turn for support, and to assist them to incorporate spiritual practices into their management of HIV disease.

As part of a study grounded in social construction theory, Wright (2003) examined spirituality as a coping mechanism among nine African American HIV infected women. Through in-depth interviews, participants defined the meaning of being diagnosed with HIV/AIDS and how it impacted their lives. The women all progressed in "moving from seeing themselves as dying to recognizing how they could, in fact, live with AIDS" (Wright, 2003, pg. 142). Four common themes emerged from their narratives: separating oneself from the victim role, a new reason to live, gaining the strength to go on, and spirituality – individualized definitions. For these eight women, viewing themselves as women with AIDS and not AIDS victims was important. All of the participants spoke about HIV/AIDS forcing them to look at their lives and their relationships with life. Their sources of strength came through hope, a return to Christianity, and drawing on relationships with ancestors. The participants gained strength through personal relationships with God, whether they were private or within more public religious practices, such as involvement in churches. For all of the nine participants, relationships with ancestors fortified them as they lived with dying. Although the participants had individual definitions of spirituality, common to their

spiritual beliefs was that life has meaning and purpose. All of the participants spoke of HIV/AIDS as a blessing, whether it provided the opportunity to become connected with themselves or others, to set things straight in their lives, or to change their relationships with life. They believed that it would have been more of a tragedy to give up on hope and faith than to die with HIV/AIDS. Spirituality was central in reframing their lives as being meaningful.

Prado and colleagues (2004) conducted a study of 252 urban, low-income HIV-positive African American mothers to examine religion within a stress process framework and to evaluate the relationship between religion, social support, coping mechanisms, and psychological distress. The researchers postulated that religion would mediate the relationship between stress and psychological distress and social support and coping would mediate the relationship between religion and psychological distress. Social support and coping mediated the relationship between religious involvement and psychological distress; however religious involvement did not mediate the relationship between stress and psychological distress. Religious involvement was directly related to higher levels of active coping and high levels of social support. Active coping was negatively related to psychological distress. The authors concluded that given the importance of religion in the African American culture, promoting involvement in religious practices may attenuate psychological distress in HIV-positive African American women.

Polzer Casarez and Shandor Miles (2008) conducted a qualitative descriptive secondary analysis to explore how spirituality affected 38 African American HIV-seropositive mothers of seropositive infants. Three overarching themes were explicated

from the data analysis: God in Control, God requires participation and the consequences of their relationship with God, specifically for themselves and their infants. Participants believed that God controlled all aspects of their lives and provided strength to manage their lives. They also believed that they had to be active participants in their relationship with God, through prayer, reading the Bible, and other spiritual practices. By participating in these spiritual practices, they believed that God would respond to their needs. Because of their belief that God was in control, through active participation with God, they were able to decrease their distress about living with HIV and, in particular, their concern about dying. Additionally, they managed their concerns about their infants through their relationship with God, believing that God would take care of their children. As a result of strong spiritual beliefs, the participants experienced less stress and fear related to their children's health and their diagnosis.

Spirituality is an important component of living with HIV for African American women. Two studies explored the public and private practices of spirituality and religion. In one study, HIV infected women did not draw upon public religious practices as often as HIV-negative women, possibly due to social isolation and the stigma associated with HIV-infection. Further information is needed to understand the public practices of spirituality and what factors influence disengagement in public practices of religion, particularly because of the importance of the Black church in African American women's lives. Three of the five studies examined spirituality in the context of being HIV infected mothers and mothering children with HIV-infection. Few studies have explored spirituality in the totality of the experience being an African American woman living with HIV infection.

Summary of the Literature

The review of the literature pertinent to African American women living with HIV-infection suggests that multiple complex factors, including the triad of sexism, racism, and classism, influence their risk for and disease trajectory of HIV infection. Watkins-Hayes (2008) states that there has been extensive research on the psychological impact of living with HIV infection, however, less is known about the everyday experiences of individuals living with HIV and AIDS. Even less is known about the everyday experiences of African American women living with HIV infection. There have been studies conducted examining medication adherence and barriers and facilitators to such treatment among African American women with HIV disease. There have been studies that have explored spirituality and religion in the lives of these women, evaluating how they define, draw upon spirituality in the context of HIV infection, and use spiritual practices to manage their disease. Last, there have been studies that have assessed how African American HIV infected women engage in self-care practices to be a mother, to influence quality of life, and to manage their disease. In summary, socio-cultural factors shape the lives of HIV-infected African American women and how they manage their disease, including their ability to adhere to medication treatments, their unique self-care practices, particularly as mothers of HIV-infected children. Spirituality is used to make meaning in their lives.

Gaps in the Literature and the Need for this Research Study

What is lacking in the literature is an understanding of how young HIV-infected African American women portray the everydayness of their lives while living with HIV and how the everydayness of their lives may be affected by spirituality and the

integration of self-care practices to support health. Previous studies have examined spirituality and self-care behaviors, albeit, within the context of coping, quality of life, or being a mother. Although this research provides an understanding of the constructs of quality of life, coping, and being a mother within the context of living with HIV infection, the specific focus has been on examining spirituality and self-care behaviors within these constructs. There is little research focusing on the totality of the experience of living with HIV-infection. Such research is necessary to explore if there are additional factors in the everydayness of being an HIV-infected African American woman which hinders or facilitates spirituality and self-care behaviors to support the complex construct of health in the context of living with a chronic, incurable, and eventually, life-threatening disease.

Chapter Three: Methodology

The purpose of this study was to explore the lived experiences of young African American HIV infected women and to explore their meanings of spirituality and self-care. The methodology used was Heideggerian hermeneutical phenomenology.

Heidegger's methodology focuses on the understanding of what it is to be in the world and understanding a phenomenon in the everydayness of an individual in the context of larger human existence. The first section discusses the philosophical framework, and rationale for using this methodology. The next section discusses the study sample, data collection procedures, data analysis, methodological rigor, and ethical considerations.

Philosophical Background of Heidegger

Martin Heidegger was one of the most prominent and influential philosophers in the 20th century. His seminal work, *Being and Time*, has been appreciated as one of the strongest anti-subjectivist explorations of what it is to be human and how humans encounter and deal with their world with concern, while entrenched in real life situations, and moving prospectively from these situations (Moran, 2000). What began with the writing of *Being and Time*, namely asking the question of being, continued as the singular pursuit of Heidegger's thoughts and writings throughout his life.

Heidegger, interested in understanding what it means to be human, sought through an examination of philosophy, to go to the root of the traditional Western philosophical conceptions of being (Palmer, 1969). He wanted to understand the basis of being. To do this he needed a method to make visible the pre-structure on which these philosophical conceptions of being have been based. His investigation began with a critique of Western philosophy and specifically its understanding of being. For

Heidegger, understanding the question of being is at the basis of everything, a fundamental ontology. Being had become lost in epistemological based understandings of being (Heidegger, 1962), which began with Plato and continued with Descartes and Kant up to the point of his mentor, Husserl.

Phenomenology opened up the world of pre-conceptual or a primordial understanding of phenomena. Husserl's approach to phenomenology however was to bring into view the functioning of human consciousness as transcendental subjectivity. Heidegger thought that this epistemological approach to phenomenology continued the subject-object dichotomy found in previous Western philosophy. Heidegger differed in that he believed the facticity of being is more fundamental than human consciousness and human knowledge. "The concept of 'facticity' implies that an entity 'within-the-world' has Being-in-the-world in such a way that it can understand itself as bound up in its 'destiny' with the Being of those entities which it encounters within its own world" (Heidegger, 1962, pg. 82). Heidegger began re-asking the question of being, grounded in a fundamental ontology. Heidegger realized that his pursuit of this fundamental ontology was suited to the methodologies of phenomenology and hermeneutics which he redefined in *Being and Time* as a Hermeneutics Phenomenology. "Phenomenology of Dasein is hermeneutics in the original signification of that word, which designates the work of interpretation" (Heidegger, 2008, pg. 84).

In *Being and Time*, Heidegger conceptualizes Hermeneutic phenomenology as the interpretation of the lived experience of humans to get at the meaning of being. Drawing upon Greek philosophy, Phainomenon is "that which shows itself, the manifested, the revealed" (Heidegger, 2008, pg. 73). Then the Phainomena or

phenomena is the totality of that which comes to light or “can be brought to the light.” Logos, derived from Greek philosophy, lets something be seen or appear. Logos for Heidegger was conveyed through speech. Speech, or more broadly, language, allows the phenomenon to be revealed. Language in the form of speech, nuances, and movement, reveals the nature of the phenomenon. Phenomenology, in the interpretation of the Greek roots of phenomenon and logos, is a means of letting the phenomenon be seen as itself (Heidegger, 2008). Heidegger, again returning to the Greek roots of language, defined Hermeneutics as interpretation. “Thus phenomenology means to let that which shows itself be seen from itself in the very way in which it shows itself from itself” (Heidegger, 1962, pg. 58). The phenomenon reveals itself, its meaning, modifications, and derivatives (Heidegger, 1962).

Whereas Husserl phenomenology is a descriptive phenomenology that only allows the meaning of being to be conceptualized in human consciousness or through the categorization of its multiple layers and it continues the subject-object dichotomy, Heideggerian Hermeneutic phenomenology is aimed at understanding the essence of being in its totality. Thus, it is an interpretive phenomenology. For example, if Husserl were to talk about a table, he would describe it in terms of its shape, its color, and the materials from which it was made. Heidegger would interpret the meaning of the table. The table was a place where the family had their nightly dinners, engaged in conversations about their lives; the table was a place that the serious writer sat at daily, working on a book of poems.

For Heidegger, understanding the meaning of being was central to his philosophy. Man questions his own being and that of other things in the world. “He is

always aware... of his being in the world” (Heidegger, 2008, pg. 19). “Dasein is an entity which does not just occur among other entities... Dasein always understands itself in terms of its existence – in terms of a possibility of itself: to be itself or not itself” (Heidegger, 1962, pgs. 32 – 33). Hermeneutics is an interpretation of the human existence of Dasein; the essence or the totality of being human. Simply understanding being is not enough, because beings are constantly changing in every moment. This interpretation of ‘existentiality’ is as the analysis of Dasein’s authentic possibilities of being (Heidegger, 1962).

To understand Dasein, ways of accessing and interpreting must allow Dasein to show itself in and from itself. One way of understanding Dasein is through its average everydayness (Heidegger, 1962). Therefore, understanding human beings must be understood from the perspective of their average everydayness. From this perspective, Heidegger names certain structures of Dasein or human existence such as its thrownness, historicity, being-in-the-world, being-with-others, and temporality. Thrownness, in which man is thrown into an already existing world, is a determinant of his way of being. Human being is a historical being, situated within a specific place, and in the context of other beings. It can only be understood within its involvement in the world, being-in-the-world, and inter-relational context of being-with-others.

Heidegger’s idea of temporality perceives the being-in-time differently from a more traditional view of time. Beings are situated in the world where time is not conceptualized in isolated segments but experienced in a constant inter-relational movement of time as past, present, and future. This is because time is experienced pre-

conceptually in the everyday world of Dasein as an interrelated whole, always transient and moving.

Ontology, must as a phenomenology of human existence, become a hermeneutic or interpretation of its existence through identifying the structures, or the inter-related parts, of human being. Only in this way can the being of Dasein be brought to show itself. It is the primary act of interpretation which brings a phenomenon out of concealment.

Justification for Use of Heideggerian Hermeneutic Methodology

The research methodology for this study was Heideggerian Hermeneutic phenomenology. African American women are “thrown” into an existing world that in part determines how they situate themselves in their average everydayness. A history rooted in slavery and oppression contextualizes the facticity of their lives that influences their present being-in-the-world and how they engage with others, often in the context of current racism, classism, and sexism. African American HIV-infected women additionally live with a chronic and life-threatening disease, which determines their present lives and either opens up or closes off possibilities for their future.

The aim of the study was to explore the lived experiences of African American women living with HIV to identify structures of their existence and to identify common understandings and shared meanings that may shed light onto how health care practitioners can support their overall health. As such, Heideggerian Hermeneutical phenomenology was an appropriate methodology to answer the research questions: 1) What is the lived experience of young African American HIV infected women? 2) How do young African American women living with HIV infection define the meaning of spirituality in the lived experience of being HIV-infected? 3) How do young African

American women living with HIV infection define and practice self-care behaviors in the context of HIV infection?

Researcher Training in Heideggerian Phenomenological Research

My education in Heideggerian Hermeneutic methodology included attending the Institute for Heideggerian Hermeneutic Methodologies in 2008, extensive readings in Heideggerian Hermeneutic phenomenology, and drawing upon expertise of faculty members well-versed in phenomenological research methodologies. Additionally, I attempted to understand the complex, contextual lives of African American women through extensive readings in Black feminist theory and Womanist inquiry. I spent ten months as a Peace Corps volunteer in South Africa, working closely with African women in educational programs about HIV prevention. I bring to this study experiences working with vulnerable women that have assisted me in the research process.

Sample

A purposive sample of eleven HIV-infected African American women living in or near a Midwestern metropolitan city participated in the study. Per Hermeneutic phenomenology, the sample size is considered adequate when the interpretations are clear, new participants do not reveal new findings, and meanings for all of the previous narratives become redundant (Crist & Tanner, 2003). The researcher recruited participants until there were no new findings in the first and second interviews. A sample size of eleven is congruent with the average sample size of ten to fifteen participants in phenomenological nursing research. Inclusion criteria identified women between the ages of between 18 and 35 years of age, African American ethnicity, HIV- seropositive, U.S. born, and the ability to speak and read English. Exclusion criteria included a

neurological disorder that affects cognition, such as dementia due to HIV/AIDS. As a nurse who has worked with individuals with cognitive disorders in the neurology setting, I was able to evaluate the cognitive status during the initial telephone call or in person during recruitment in the clinic setting.

Table

Description of Sample

	N	Mean	Range
Age in Years	11	25	21 - 35
Educational Level in Years	11	12	8 – 14
Number of Children	11	1.8	1 - 5
Number of Children at Home	11	1.2	1 – 5
Years Living with HIV	11	7.45	1 - 22
CD4 Count	4	608	300 - 760
Viral Load	2	5630	1260 – 10,000

Note: The N is much smaller for Cluster of Differentiation 4 (CD4) counts and viral loads as many of the women did not know their CD4 counts or viral load. Two women did not know the specific viral load, but reported that it was non-detectable.

Recruitment

Due to the difficulty in obtaining an appropriate sample size in an 18-month period, several methods of recruitment were employed, including dissemination of an informational flier (Appendix A) in three settings: Ryan White Case Managers and Family Case Managers, at a metropolitan infectious disease clinic at which one of the co-

researchers was an Advanced Practice Nurse, and by meeting with women at a metropolitan infectious disease clinic, at an academic-affiliated infectious disease clinic.

Assistance from Case Managers

Originally, I planned to recruit participants through Kansas City Free Clinic Family Case Managers and Ryan White Case Managers, who were employed at multiple Infectious Disease clinics and agencies that provided services within the metropolitan area. After appropriate approvals were obtained (Appendix B and C), the case managers disseminated the informational flier to their clients and explained the purpose of the study. I recruited two participants through the Case Managers.

Assistance from a Metropolitan Infectious Disease Clinic

After appropriate approval was obtained (Appendix D), I expanded recruitment to a metropolitan infectious disease clinic that serves a large population of African American HIV-positive women in the metropolitan area. The advance practice nurses disseminated the flier to their clients who met the inclusion/exclusion criteria at clinic appointments. Additionally, I attended the clinic to personally meet the women and explain the study and set up a time for the informed consent process and initial interview. Nine participants were recruited through this clinic. Of the nine women, four were recruited by an Advanced Practice Nurse who was the primary provider for this population. The other five women were recruited by me, when I personally met them at their appointments. This was the most effective form of recruitment, as it allowed the opportunity for the women to meet me and discuss in person the study; rather than the women calling an anonymous person whom they have never met and share that they are HIV-positive in a telephone conversation.

Assistance from an Academic-Affiliated Infectious Disease Clinic

After appropriate approval was obtained (Appendix E), I expanded recruitment to an academic-affiliated infectious disease clinic. Although at this clinic, there was only a small number of African American HIV-positive women, physicians disseminated the informational flier to those clients who met the inclusion/exclusion criteria at their clinic appointments. One client expressed an interest in the study, but was undergoing treatment for pancreatic cancer and decided that she could not participate in the interviews.

Amendments and Compensation

At each step in the research process in which I expanded recruitment, appropriate amendments were made to the Human Subjects Committee protocol for recruitment at these sites. The Institutional Review Board (IRB) approval letter and IRB-stamped consent form are found in Appendices F and G. Originally, I planned to compensate the participants with a twenty-dollar gift card for each interview. However, prior to any enrollment in the study, and with IRB approval, I increased the compensation to forty dollars per interview. Because there were not any women who had enrolled in the study, I was concerned that twenty dollars was not sufficient compensation. I received funding for participant compensation through a grant from Kansas University Nurses Alumni Association, which allowed me to increase compensation.

Data Collection Procedures

Setting

In qualitative research the researcher seeks to understand the lives of individuals within their natural world setting. This allows for the researcher to understand the

context of their world, such as in their homes or communities. However, being in their natural world may make women uncomfortable, as they were sharing very private information and not all of their family members were aware of their status. Thus the interviews were conducted in the environment deemed most comfortable for the participant. Of the eleven participants, eight preferred to be interviewed in their home. Two wanted to have the interviews conducted in a private room at a nearby public library. The eleventh participant wanted to meet at my office, in a School of Nursing. Having the participants choose the setting in which they would be most comfortable allowed them to create a safe place to share their stories, which was important to the story-telling process.

Interview Process

The object of hermeneutic phenomenological writing is to develop a phenomenological text (Van Manen, 1990). Interviews as a narrative “facilitate the inscription and visibility of the lived experience” (Manderson, Bennett, & Andajani-Sutjahjo, 2006, pg. 1318) and are a common form of text used in phenomenological nursing research. Oral narratives reveal cultural and social patterns through the lens of the individual’s experiences (Patton, 2002), which is important as I was extremely concerned that the stories told were true to the women. Interviews as a narrative text were the means of understanding the concrete experiences of African American HIV-infected women and how these experiences formed an interpretive understanding of their lives.

Interviews are influenced by how they are conducted, by whom, and the environment in which they occur (Manderson, Bennett, & Andajani-Sutjahjo, 2006).

Additionally, a concern that has arisen in terms of interviewing within qualitative research is the influence of the social constructs of age, class and gender of the researcher and participants and how these social constructs may influence the interview process. Although this does not make the interviews and information derived from the interviews invalid, it is a concern of which the researcher should be aware (Manderson, Bennett, & Andajani-Sutjahjo, 2006). Again, by beginning the interviews with an informal dialogue that opens up the possibility of care, trust, and a reciprocal relationship may help assure that the social constructs of age, gender, and class will not negatively influence the interview process. I was concerned about the social construct of class, which did influence my ability to ask the participants their economic status. I believe that this information would have provided a deeper understanding of their lives. I could garner from the physical space in which I interviewed many of the women that there were often financial constraints that likely influenced their lives. As they were prepared to share their private lives, I did come to the interviews with care and concern for them to assure that there would not be barriers in the interview process. And believe that I was able to develop a trusting relationship.

At the initial interview, I provided a detailed description of the study, including basic questions that would be asked. I also reviewed the informed consent process (Appendix G), and obtained basic demographic information (Appendix H), used to describe the study population. I then conducted an unstructured interview, which was audio-taped. The interviews were unstructured to facilitate an honest dialogue between the participants and me. Because the interviews were unstructured, I did not have a specific list of questions to ask, but did initiate the interview with the prompt: Please tell

me a story that describes your experience of living with HIV infection. Example prompts to further elicit information included, Can you describe (specific topic) further? How has HIV influenced your life? What gives you hope or strength? To uphold the concepts of caring and trust, I began the interview with an informal dialogue that was not audio-taped, in which the participants and I had the opportunity to get to know each other. I introduced myself, including why I was interested in conducting this research study, sharing my experiences working with South African women. Before beginning the interview, I gathered the demographics, which usually provided the opportunity for the participants to share stories about their lives, most often about their children.

Oral narrative research with African American women may be challenging for researchers because the linguistics and cultural nuances are both rich and complex, thereby complicating the transcription of the audio-taped interview (Pennington, 1999). In addition to the audio-taped interviews, I tried to take notes, to comment on non-verbal forms of language, including gestures, body language, and emotional expressions, to assist me to recall how women conveyed their stories during the interview. However, in the first two interviews while taking notes, I felt distracted and was concerned about being perceived as disrespectful of the women as stories were shared. Thus I jotted notes after the interviews and immediately listened to the audiotapes after the interviews to assure I had captured the stories correctly. Upholding the concepts of caring, trust, and the personal responsibility towards the participants, if participants became visibly upset during the interview I stopped the audiotape, which I had to do twice. All of the participants wished to complete the interviews. I included a list of mental health care sources (Appendix I), such as 24-hour crisis-lines, in my research notebook to provide to

the participants in the event that the participants needed immediate mental health services. I did not have to refer any participants to these services in either of the interviews.

Interviews were repeated with the participants, per Hermeneutic phenomenological research (Ironsides, 2008), to gain deeper insight through the co-creation of the researcher and participants of substantive themes (Crist & Tanner, 2003). The second interview was conducted to provide clarification of information from the first interview and to garner additional information that further described and interpreted the experience of living with HIV infection. At the second interview I verbally reiterated the informed consent process, and again conducted semi-structured interview to seek clarification and to expand upon ideas developed from the initial interviews. The second interview began in a similar manner as the first, in which there was an informal dialogue between the researcher and the participant, to establish a trusting and respectful relationship. Salient points from the initial interview were introduced, with the prompt: In our first interview, you told me your story about living with HIV infection. Could you discuss (topic) further? Three women could not be reached for second interviews due to dis-connected telephone numbers; thus I used the initial interviews for the data analysis. Interestingly, two women, whom I initially was unable to contact, called me to set up the second interview. During their second interviews they had more to share about living with HIV.

Data Analysis

The hermeneutic process described by Pam Ironside, PhD, RN, the facilitator at the 2008 Institute for Heideggerian Hermeneutic Methodologies and the interpretive

process outlined by Van Manen (1990) were used as guidelines for the data analysis. Appendix J depicts the data analysis process. Hermeneutic phenomenology is circular, reflexive, and never ending in that the interpretation of the meaning or essence of being is always in the context of historicity and facticity, both for the researcher and the participant. Therefore, it can be an ongoing process of continual interpretation of the data. However, to disseminate the findings, to integrate the findings into practice and develop new research questions in a timely manner, I discontinued the interpretative process after developing two stories. Although the data analysis process as depicted in Appendix H appears linear, there was fluidity between each step in the analysis. The process was not linear, as I went back and forth through many of the steps, reading the narratives and writing the stories, writing the stories and re-reading the narratives to develop the initial themes, developing the initial themes and writing the second stories, comparing the second stories to the first stories and initial themes, and developing the final pattern and themes and then revising the second stories.

Because human beings are unavoidably rooted in the facticity of everyday existence, hermeneutic phenomenology moves in a requisite cyclical interplay between the experience of the examiner and that of the examined (Moran, 2000). As such, the researcher brings to the research her or his own experiences and assumptions about the phenomenon to be studied (Allen, 1995); instead of “bracketing and setting aside their biases, they are explicated and integrated into the research findings” (de Witt & Ploeg, 2006, pg. 216). This allows for a more fundamental interpretation of the stories provided by the participants. Thus, I kept a reflective journal in which I shared my ideas, feelings, and perspectives that would influence my interpretation of the participants’ narratives.

The interviews were transcribed verbatim in the conversational language to ensure that the linguistics and cultural nuances were revealed. Any information that could identify the participant was removed from the transcripts. The transcribed texts were read in their entirety while listening to the audio-tapes for accuracy. The texts were re-read at least twice to develop a first story that described and interpreted the experiences of each woman with initial themes explicated. This was completed for each text. Six of the first stories were shared with a research team member, who also read several of the interviews. We met to discuss the stories, share our initial themes, and further develop the initial themes. The second stories (Appendix K) were developed, again that described and interpreted the participants' experiences, with further themes explicated. The first and second stories were developed and written using the transcripts, notations I made during the interviews, my thoughts about the interviews from my journal entries, and discussions with one of the research team members. Last the pattern and four themes were reviewed with a research team member and revised. The pattern and themes that I eventually developed were through a compilation of all of this data and not only based on the interviews with the participants. The pattern and themes were discussed extensively with the research team member to assure they were true to the experiences shared by the women.

Additionally the first themes and second themes were shared and discussed with a peer debriefer, who recently completed a Hermeneutic phenomenological study and was familiar with the analytic process. She offered significant insight into the themes that were developed, challenging themes that were unclear and offering support for themes that resonated based on the information provided to her. Literature, including

phenomenology and feminist theory, was reviewed and integrated into the interpretation of the themes and patterns.

Although I did not take many notes during most of the interviews, I wrote information after the interviews, incorporating this information as well as my reflections into the analysis. The final analysis, describing and interpreting the lives of the women living with HIV through the development of one pattern and four themes, was constructed using the interviews, the first and second stories I developed as an interpretation of the stories told, my reflective journal, and dialogue with the peer debriefer and a member of my research team. Words and phrases I used both in the stories and the findings were not necessarily words or phrases the participants used. They were words and phrases that I thought best exemplified the participants' experiences living with HIV. The analysis procedure was guided by immersion in Heidegger and Van Manen's philosophies, particularly the idea of looking for what is hidden in the everydayness of the phenomenon; the understanding of living with HIV infection, spirituality, and self-care management from previous literature to assist in the interpretive process.

Methodological Rigor

There has been considerable debate regarding methodological rigor in phenomenological nursing research. One of the main themes emerging from the debate is that rigor established for generic qualitative research is not sufficient for expressing the rigor of interpretive phenomenology (DeWitt & Ploeg, 2006). Searching the literature of phenomenological research specific to rigor, DeWitt and Ploeg found a broad range of criteria of rigor. Some authors suggested using traditional qualitative criteria, such as

trustworthiness, auditability, confirmability, credibility, and transferability. Others suggested criteria that emphasize unique features of phenomenology, such as richness, integration within the research findings philosophical concepts, opening up the inquiry process to others, and understanding that the process of interpretation does not end with the completion of the study. The framework DeWitt and Ploeg developed incorporates criteria that support the unique features of interpretive phenomenology: balanced integration, openness, concreteness, resonance, and actualization. Four of these criteria of rigor were used to ensure methodological rigor in this study.

Balanced integration, which reflects rigor in the research process, includes three components: articulation of the general philosophy and its fit with the research topic, in-depth intertwining of philosophical concepts, such as temporality, into the research methods and findings, and a balance between the voice of the study participants and the philosophical explanation. In providing a detailed understanding of the philosophical underpinnings of Heideggerian hermeneutic phenomenology and rationale for using this methodology for this research study demonstrated articulation of the general philosophy and how it fit with the study of the lived experience of African American HIV-infected women. In the discussion of the findings, I integrated philosophical tenets of Heidegger's philosophy that supported the interpretation of the narratives to develop the themes and pattern. I tried to balance the voice of the study participants with the philosophical explanation. During a telephone call after the interviews, I provided the patterns and themes to three of the participants to ensure that these themes and patterns remain true to the voices of the participants. The three participants agreed the pattern and four themes interpreted their stories of living with HIV. One participant disagreed with

the idea of the possibility of an early death. This was interesting, because during her interview, she expressed concern about dying.

Openness reflects rigor in the research process. It is opening the study to scrutiny, through an explicit systematic display of decision-making. Rodgers and Cowles (1993) suggest several strategies for maintaining a detailed audit trail of the research process, including fieldnotes, methodological documentation, analytic documentation, and personal response documentation. I used these processes to ensure openness as a criterion for rigor.

Concreteness is a reflection of rigor in the research outcomes, in which the findings are written in such a way that the examples provided situate the reader concretely in the context of the phenomenon being explored and can link to experiences within the reader's worldview (DeWitt & Ploeg, 2006). Additionally, the findings of the study are useful for nursing practice. I provided a rich description of the findings, incorporating excerpts from the narratives that exemplified the themes and pattern to promote the ability of the reader to be situated in the context of the phenomenon of being an African American HIV-infected woman. Implications for nursing practice, education, health care policy, and further research were discussed in chapter five to ensure concreteness as a reflection of rigor.

Resonance is a reflection of the research outcomes. It encompasses the experiential effect of reading the study findings, in which the reader develops an intuitive or empathetic grasp of the meaning of the phenomenon. This was accomplished through a rich description of the patterns and themes, again incorporating excerpts that provided

an intuitive understanding among the readers of the experiences of African American women living with HIV.

Actualization, the last criterion of rigor in the research outcomes, “addresses future realization of the resonance of... study findings” (DeWitt & Ploeg, 2006, pg. 226). Researchers suggest that the phenomenological interpretation does not end when a study is completed, implying that the findings of a study will continue to be interpreted by future readers (DeWitt & Ploeg, 2006). Because there are not formal mechanisms in place to measure actualization, this criterion for rigor was not used in the present study.

Ethical Considerations

Cutcliffe and Ramcharan (2002) posit that ethical issues need to be considered in research in which there are prolonged relationships with vulnerable populations. As with any type of research involving individuals, the research must display minimal potential harm to the participant. To assist in ensuring that the present study poses minimal harm to the participants, review of the study protocol and approval from the Institutional Review Board at the academic medical center at which I am a doctoral student was obtained prior to commencement of the study. I completed the Institutional Review Board Research Conduct of Scientific Research modules and passed the exam; this provided documentation that I have been trained in ethical conduct of scientific research.

Although some researchers suggest that discussing sensitive issues may be traumatic for participants, others suggest that the opportunity to discuss their experiences may lead to reflection or catharsis (Cutcliffe & Ramcharan, 2002). In this study, questions asked about the experience of being HIV-infected could have caused emotional distress. All participants were given the opportunity to withdraw at any time during the study.

Participation was completely voluntary and opting to not participate, to only answer a portion of the questions, or to quit during the study did not adversely affect women's health care at the clinics that they attended for treatment of their disease. There was no evidence of harm by participating in the study. The participants chose to share their stories.

Issues of trust and informed consent are not a singular event, but must be established and ongoing throughout the research process (Cutcliffe & Ramcharan, 2002). Informed consent from the participants was gained prior to data collection and was continually appraised during data collection. Because qualitative research is conducted through a prolonged, intimate engagement with the participants often with the goal of understanding a phenomenon, the researchers and participants enter into a dynamic, interactive relationship in which rapport and trust are necessary (Cutcliffe & Ramcharan, 2002). I attempted to develop trusting relationships with the participants at the time of the initial informed consent, upholding the values of respect, dignity, and empathy, and continued to build these relationships at the second interview. Because the data were collected in person, I could not assure anonymity to the participants, but did assure confidentiality, using pseudonyms in the research findings. I asked the women if they wanted to create a pseudonym for their narratives; only one woman chose to do so. I chose the rest of the pseudonyms. To further assure confidentiality of the participants, the audio-tapes and transcripts were kept in a locked file in my secure office. The audio-tapes and transcripts will be retained per protocol.

Chapter 4: Findings

The lived experiences of eleven young African American HIV-positive women were characterized as Infected Lives, as HIV has invaded every aspect of their being. Infected Lives, the constitutive pattern, is supported by four relational themes, 1) Living Alone with HIV, 2) Living with Unresolved Conflicts, 3) Living with Multiple Layers of Betrayal, and 4) Living in the Everydayness of HIV. The first part of this chapter is a brief introduction to the women. I developed the descriptions of the participants using components of the longer stories found in Appendix I. The participants are introduced in alphabetical order. The pattern and themes are then discussed.

Participants

Alisa

Alisa is a 35-year old woman, married with five children. Alisa's life changed forever when pregnant with her fourth child, she found out she was HIV-positive. Newly married, her first reaction was to tell her husband, who is HIV-negative, to walk away from the marriage. Alisa has been juggling living with a lifelong, fatal disease (Alisa's perspective) and being a wife and mother. Though not always spiritual, Alisa now draws upon a strong belief in God for strength. She suffers from severe mood swings, as a result of knowing she has an incurable disease. Alisa wants to be prepared for when she dies, ensuring that her children are taken care of. This is a real concern, as her children are all from different partners.

Diana

Diana is a 24-year old woman, pregnant with her first child. Diana was diagnosed while she was 17 years old. Although she had a premonition that she was HIV-positive,

she was devastated when she got the positive results. Without a deep belief in God and the birth of her first nephew, she would have committed suicide. She continues to have pervasive depression, for which she sees a counselor. She also prays nightly as another way to cope with the depression. Her baby gives her hope for the future; however, the future is very different from what she had envisioned prior to her diagnosis.

Dion

Dion, a 22-year old new mother, was diagnosed during her first pregnancy less than one year ago. Having had a recent negative test, she was shocked and hurt when her test came back positive. Her boyfriend has also tested positive. Despite her initial feelings of betrayal, Dion has resolved her anger toward her boyfriend and has remained in a relationship with him. Caring for a new baby, they both have to learn to live with HIV-infection, thus are a support to each other. Dion's family has also provided support. Outside of the family, Dion is very careful to keep her status private. Dion seeks comfort in her daughter as a way to cope with the depression that has been present since her diagnosis.

Dutchess

Dutchess, a 27-year-old single mother of an adolescent son, was diagnosed less than two years ago. Having recently had a negative test, Dutchess was tested again as part of a routine work-up for life insurance. She was shocked when she was denied insurance and contacted by the Health Department. Initially overwhelmed and devastated, she quickly became involved in support groups and HIV classes to be educated and informed. She has a deep faith in God and, since her diagnosis, a clearer picture of where she wants to be spiritually. Still dealing with depression as a result of

her diagnosis, Dutchess' son gives her hope for the future. Without him she may have given up on living. Dutchess is now a certified peer educator and planning to become a behavioral specialist and continue to work with HIV-positive individuals.

Jacqueline

Jacqueline, a 22-year old, lives with her two-year old son in a small town outside of the metropolitan area. Diagnosed at birth, she did not find out she was HIV-positive until she was a teenager. Her mother died from AIDS related causes, when Jacqueline was a toddler; she was raised by an Aunt and then by her older sister. Despite a prolonged serious HIV related hospitalization as a teenager, resulting from her quitting her medication therapy, Jacqueline has recently stopped taking her medications. Depressed and searching for meaning in her life, she talked about recent suicidal thoughts and that she had considered giving up her son for adoption. Her son provokes hope for the future, but it is not enough. Without any spiritual beliefs, Jacqueline has little support in her life.

Katelyn

Katelyn, a 22-year old single mother of a young daughter, was diagnosed four years ago during routine prenatal care. Upon finding out that she was HIV-positive, she went into an intense depression, from which she has not recovered. Feeling very exposed in public, she frequently stays in the safety of her home. Katelyn was initially very angry at God and would not pray or attend church services. Her faith in God is now very important to help her cope with living with HIV infection. Although trained as a peer educator, she is not ready to work with other HIV-positive individuals; that would be

another unwanted reminder of her diagnosis. She has little hope for the future and shared her anguish at the possibility of leaving her daughter.

Lizbeth

Lizbeth, a 21-year old new mother, was diagnosed four years ago. She was shocked when her boyfriend told her he was HIV-positive and devastated when her test was positive. Having resolved her anger and feelings of betrayal, she has remained in a relationship with him. Lizbeth has not disclosed to her parents and family. Only her boyfriend, his immediate family, and her healthcare providers are aware of her status. Despite being able to talk to her boyfriend, Lizbeth feels a void of relating to women and would like more support. However, she is not ready to take a risk and disclose to family or friends. She is depressed and would like to work with a counselor, but has not yet made plans to achieve that goal. Lizbeth is spiritual and attends church and bible study regularly. She draws upon her spirituality as a way to stay strong and positive. Her daughter provides hope for the future.

Mikayla

Mikayla, a 27-year old, was diagnosed four years ago during routine prenatal care. Although devastated, she had a premonition about the diagnosis. Mikayla became very depressed and suicidal. Her boyfriend convinced her to not act on her suicidal thoughts, reminding her that she needed to live for the baby. Mikayla is still very angry at the man who transmitted the virus to her. Feeling betrayed by him, she now holds a lot of anger toward men in general. She also is angry at herself, feeling disgusted about having HIV-infection. Mikayla has nothing to provide hope for the future. Her relationship with her family is tumultuous and violent, her children were taken away from

her, her boyfriend is incarcerated, and she feels that God betrayed her multiple times. Although the walls in her small apartment often feel constraining, this is the only place where she really feels safe.

Natalie

Natalie, a 21-year old mother, became infected after she was unintentionally stuck with a “dirty” needle that her parents, who both were intravenous drug users and HIV-positive, had left lying around. An aunt adopted her and her eight siblings and moved them to the Midwest. Natalie grew up very lonely, not allowed to play with other children or attend activities with her siblings. Unaware of her diagnosis, she did not understand her Aunt was trying to protect her. Learning that she was HIV-positive as a teenager provoked a severe depression, which has remained. It can be so severe that Natalie questions if she wants to live. However, Natalie has a young daughter who gives her hope. Isolated because of a lack of transportation and because she does not maintain relationships with friends as a way to prevent them from finding out she is HIV-positive, Natalie has limited support. She draws upon her spiritual beliefs to help her cope with living with an incurable and chronic disease.

Priscilla

Priscilla, a 27-year old, pregnant with her fifth child, contracted HIV-infection from her abusive boyfriend four years ago. Currently homeless, she shifts between living with a violent family and living with her boyfriend to whom she refers as her “baby daddy”. Repeatedly raped and abused by her mother’s drug partners and foster parents, Priscilla grew up in an environment that betrayed the fundamental innocence and safety of a child. Priscilla’s siblings, whom she raised as a teenager and who stood by her prior

to the diagnosis, are now physically and emotionally abusive toward her. With no support or love from her family, Priscilla desperately wants to keep this child. Priscilla is not thinking about the future; trying to find stable housing and trying to stay healthy for her baby, she can only focus on the present.

Reandra

Reandra, a 30-year old single mother of two children, was diagnosed when she was 22 years old, homeless and living in a hotel with an IV drug user. Although Reandra initially stayed in the relationship, she eventually realized that her boyfriend's passivity and denial was negatively affecting her health. Reandra seems defeated by HIV, living a life with little meaning. Once a very active, outgoing person, she now shields herself from the external world, staying in her home most of the time. A pervasive depression, that is currently untreated, prevents her from being more active. Prior to being diagnosed with HIV, Reandra was not a spiritual or religious person. Since, she prays more often and reads the Bible, stating that they both help her spiritually and emotionally. When Reandra thinks of the future, she is inspired by her children. However, there is a lot of uncertainty, particularly for her children, if she becomes very ill.

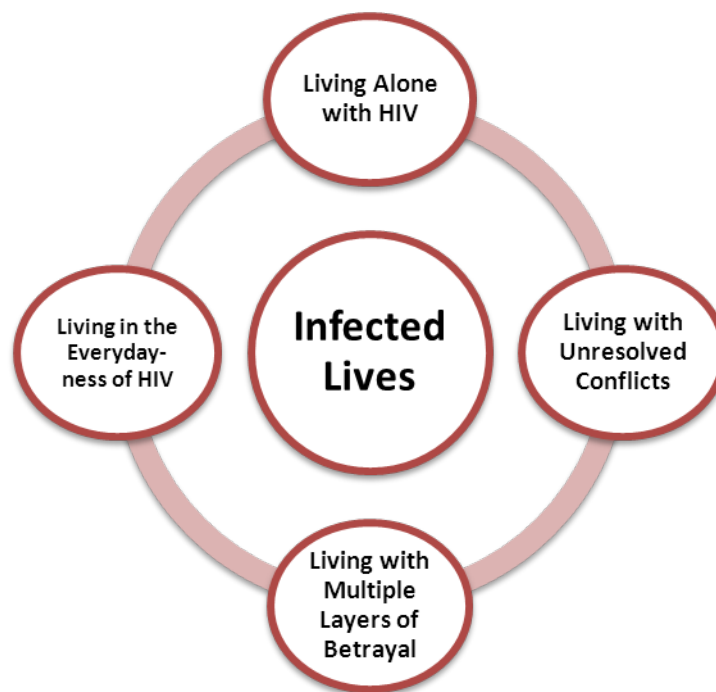
Pattern and Themes

Upon initial review of the stories, I was not sure that I had captured the lived experiences of these eleven young African American women living with HIV-disease. Heidegger suggests, "What is ontically nearest and familiar is ontologically the farthest, unrecognized and constantly overlooked in its ontological significance" (Heidegger, 1951, pg. 41). So I was compelled to look into what was hidden in the stories to gain an understanding of what living with HIV infection as a young African American woman

was in order to find and develop a pattern and themes through the interpretation of the stories. Although a pattern and four themes were explicated from the stories, the stories shared are only a snapshot of these women's lives. They do not describe the totality of the women's lives. The overarching pattern, *Infected Lives* that portrays the relational themes of *Living Alone with HIV*, *Living with Unresolved Conflicts*, *Living with Multiple Levels of Betrayal*, and *Living with the Everydayness of HIV*.

Figure

Interrelationality of Pattern and Themes



The graphic depicts that the overarching pattern, *Infected Lives*, as central and supporting of the four themes. Because Heideggerian phenomenology is a circular process, I believe that a circle is a better representation of the relationships between the pattern and the themes and between the themes than a more linear graphic would have

been. Rather than using arrows to demonstrate the relationships between the themes, the largest circle conveys that all of the themes are inter-related.

Infected Lives

The constitutive pattern, *Infected Lives*, expresses the idea that HIV has invaded the physical, spiritual, emotional, mental, and social worlds of the women. Their lives have changed in ways that they would not have imagined prior to their diagnosis. *Living Alone with HIV* describes the experience of living alone within the context of HIV, despite the often physical and emotional presence of family and friends. It also expresses that the women felt that they were no longer normal people living a normal life, further pushing them to the margins of the greater world and fully being with other people. *Living with Unresolved Conflicts* conveys that the participants, facing a chronic, life-threatening illness as young women resulted in myriad conflicts they could not resolve. The participants often felt exposed as individuals living with HIV therefore they had to protect themselves. But in doing so, they became isolated and alone. Their children provided strength and the will to live. However, young and possibly facing death, there was anguish in leaving their children. As strong mothers, they had difficulty balancing care of self and care of family. The women were externally strong, but internally fragile; the ability to voice their concerns and fears were often silenced due to their concern about stigma and betrayal.

Living with Multiple Layers of Betrayal describes the effect of stigma and discrimination on the women, damaging their trust at multiple inter-personal and social levels. Stigma and discrimination influenced their aloneness and forced them to shield themselves from the public's view and for several women from their families. *Living in*

the Everydayness of HIV developed as a theme as the participants shared multiple stories of the changes in their everyday living with HIV. In addition to managing HIV, they were now trying to cope with chronic depression. They had to learn new ways of self-care as a result of having a chronic illness. Spiritual practices were often daily self-care practices to help alleviate the mental and psychological distress. Family support was an important component of the everydayness of living with HIV. Participants who had strong family support and spiritual beliefs seemed to be able to cope better with psychological distress.

Infected Lives portray the idea that HIV has created the women's worlds, rather than the women being able to create their own worlds. They have tried to create new meanings in their lives, as who they are as themselves and within their family and the community has changed. Seeking a future that would have fulfilled them, several participants now adjusted their expectations of career goals to meet the needs of their families within their idea of the self, living with a chronic, life-threatening illness.

Infected Lives as the overarching pattern is the foundation for the four inter-relational themes that describe and interpret the lived experience of the eleven young African American women living with HIV.

Living Alone with HIV

Living Alone with HIV reflects the lives of the women, who articulated a life of being alone with a chronic, often death-defining illness. Even for the women who had supportive partners, families, or friends, there was a feeling of facing their disease by themselves. Dutchess shared "I'm like, as much as I love my boyfriend; he's negative, I love my mother. They don't necessarily understand". Alisa shared similar thoughts and

frustrations, stating “Um, sometimes with them... it’s like you don’t get it. You know cause you’re looking for them to say something to kind of help you in the moment, but when they can’t... that frustrates you even more”.

The words, “isolation” and “abandonment” were not voiced by the women, however through the stories many shared, it became apparent that they did feel isolated and abandoned. Frequently, they felt isolated from everyone else. Diana expressed “It’s like I feel like the world is against me”. Natalie shared “I just don’t feel like there’s nobody in this world that really understands me”. Jacqueline stated

And I just feel like I’m the... it’s like in Missouri, it’s a bigger city and I just feel like I’m not the only one living with HIV there and all that. But here... I do feel that, like that... I do feel that I’m the only one with HIV.

Jacqueline worked with a staff member in a program “Success by Sex”. Jacqueline shared that once the staff member found out Jacqueline was HIV-positive, she backed away. Jacqueline said “she stopped calling, she stopped coming by and all that, stopped helping out”. Feeling isolated and abandoned resulted in being alone and have helped shaped the foundation of the women’s worlds. Mikayla articulated that she has no family and nowhere to turn. With a boyfriend who was incarcerated and little family support, she has had to cope with her diagnosis by herself.

Two of the women had actually been living fragmented and chaotic lives since childhood. Spending many years in the Division of Family Services (DFS), living in foster and residential homes, their continued relationships with their families were very unstable, resulting in a world of aloneness. Mikayla, feeling abandoned by the individuals she thought would provide a safe world for her, said

I feel like I was singled out of the bunch... my sisters got to live normal lives, mine was corrupted at a young age. I was in the system twelve years. It was almost like jail.... And that's why just the thought of them when they entered back into my life, I'm like you took the best part of my life from me and every time I see them my mind goes, Lord I wish I could... put them in another state, all of them. I hate them. I resent them. To be locked up that long and get out, [after] my sister passed away, I feel like God took my best friend from me.

While in DFS, Mikayla's hope and support from her sister, an important person in Mikayla's young life, was wiped away upon the death of this sister. This episode has further negatively impacted her relationships with her immediate family.

Mikayla and Priscilla's children have been taken from them, further creating a very lonely place. A cycle of abandonment has been developed, undesired by either of the women, and has continued to infect their lives. For both Mikayla and Priscilla, the several layers of abandonment have supported that they are truly alone in their navigation through a complicated world of HIV.

Families are affected by HIV. They may react to it based on their own psychological needs. If family members feel abandoned, they may become angry, negatively affecting family relationships. Priscilla, once out of DFS and in her mother's home as a teenager, was the primary caregiver for her siblings. Upon learning Priscilla's diagnosis, many of her siblings have turned away from her. Knowing that HIV can result in an earlier death, her siblings may feel abandoned by her, the person who cared for and loved them during their formative years, negatively affecting their current relationships with her.

Living with Unresolved Conflicts

Living with unresolved conflicts exemplifies the *internal and external struggles* the women faced daily, upon learning their diagnosis of HIV-infection. I originally conceptualized this theme as duality. However duality implies a dichotomy between the subject and object, a perspective not upheld within Heideggerian phenomenology, which rather focuses on the totality of being. With that perspective in mind, I created the theme living with unresolved conflicts, as this better supported the daily struggles that the women encountered. Standing tall was another theme that I considered, as I contemplated the outward display of strength. Upon further review of the stories, I and other members of the research team recognized that behind the outward strength, was inner fragility, as the participants tried to reconcile living with an incurable, chronic disease that is ultimately defined by CD4 counts and viral loads, and the idea of death. Living strong, but still fragile is one facet of living in unresolved conflicts. The women had to be in control, as there was a lot perceived to be at stake. They may lose their children, their familial relationships, and possibly their identity, if they were seen as being weak. Thus they were *externally strong, but internally fragile*. The fragility was apparent as the women continued to articulate conflicted emotions, tensions, and experiences as they sought to build a new life that was defined by their diagnosis. The women were trying to live an honest life, confounded by a diagnosis that frequently provoked stigma and discrimination, and reconciling the risk of being honest and open with feeling dishonest, thus feeling safe. Alisa alluded to this conflict of honesty and openness versus dishonesty and protection of self, as she expressed

At a point now in my life where I want to be open and honest with other members of my family because they don't know. And I said this year will be the year that I tell them, because I don't know when is going to be my last.

Natalie shared that some of her relationships were negatively impacted by her concealment of HIV. She said

I don't really have too many friends... I mean it's kind of hard to keep friends, especially if its friends that don't know about your status and it's kind of like I don't want to go there and have to explain myself to somebody. Because eventually you have to.

The women were attempting to reconcile the conflict between their hidden life and their public life. Dutchess, discussing the change in her long standing friendships, shared

I have friends who they're seeing that there's something about me that's changing, that's different. And I've had friends that just... we don't talk... you know, I've also had other friends who, you know and I think it's weird because it's the ones who I expected to walk away when they found out are the ones who have been right by me. But the ones I've known all my life, they're just like ahh, she'll be alright.

Whether actual or perceived, they were facing death as young women. Two participants did in fact have a parent who died from AIDS related complications at a young age, thus death associated with the diagnosis of HIV/AIDS was very real.

Jacqueline lost her mother to HIV/AIDS when she was a toddler. Natalie's father died from AIDS related causes when she was six. Routinely monitoring their CD4 counts and

viral loads, they were constantly reminded that their life may very well be shortened.

Katelyn, discussing her future, said

I think it's a lot shorter [referring to her life]. Like I don't see... I don't see like, you know before I was diagnosed you feel like you have forever, you know, when you were a teenager you feel like you have forever and nothing's ever going to happen to you or whatever. But now it's more like time's just ticking, I guess. That's kind of how it feels, it's like it's going to end soon... It's not being there for memories... I think that's like the hardest thing to accept about it. I think if I didn't have her [daughter], I probably wouldn't care as much, but it just scares me for her.

The decision to disclose was a very careful consideration for most of the women, due to the risk of stigma. Katelyn articulated

Kind of like that is to me one of the scariest things other than dying from it is telling someone. Like not even necessarily a sex partner. Just telling someone because you never know like what they'll go and spread around the whole world.

Lizbeth has not yet disclosed to her family, even though she was diagnosed as a teenager. Although she thinks her immediate family will be supportive, she said "I mean it makes me feel a little bit bad about not telling them, but I just don't want my business all out there, cause they run their mouth a lot". Twenty-two years old with a chronic and potentially fatal illness, Lizbeth was so concerned about the idea of her family sharing her diagnosis beyond the family unit, that it is safer for her to keep it hidden. This concern was voiced by many of the women, resulting in a conundrum of living a private and public life with family, friends, or in their communities.

Shielding themselves from the public, the community, friends, and even family was imperative to ensure their safety. However, by *protecting themselves, they inadvertently created a world of isolation*. The women created a protected space to shield themselves from actual or possible stigma and discrimination associated with the diagnosis of HIV-infection. Although this protected space was most often their home, some of the women also created a protected, private space that was internal. Alisa shared that when she is having a tough time dealing with her diagnosis, “I just kind of go to myself and I go to my special place and I think about things and I put things in perspective”.

Reandra, educated to be a medical assistant, now stays within the walls of her home, unwilling to go out into the world as she sees it as unsafe place. Reandra stated “I just contain myself, you know, in the house. I don’t know... It’s sort of like I’m protecting myself from all bad things; everything; the world”. Katelyn, believing that everyone can see that she is HIV-positive, is not comfortable being out in her community. She completed the education to become a certified peer educator, but was not ready to reveal her diagnosis or share her story with other HIV-positive individuals. She stated

I guess that was like kind of the idea in being a peer educator, but that’s like the...

I applied to be one and I got accepted, but I guess the idea of being a peer educator was what scared me the most, it was like kind, I guess, outing yourself a little bit, that’s what it felt like and I just wasn’t really like emotionally strong enough.

In protecting themselves, isolation has become a barrier to being-in-the-world and being with other people. Practical everyday issues have also contributed to this world of

isolation. Natalie, wanting to connect with other HIV-positive women, does not have transportation to attend support groups or women's retreats. Jacqueline lives in a community that has few services for HIV-positive women.

The women historically had taken on the role of the primary caregiver in their family unit. After the diagnosis of HIV-infection, a *tension between caring for themselves and caring for their family* was present. Several of the women articulated that in order to care for their families, they needed to care for themselves; but for many, caring for their family often took precedence. Jacqueline said "I care about others... I put others before myself". Alisa stated

Even though you're thinking I'm going to go and do this for me, but actually when you go and do something for yourself, you're actually probably thinking about somebody else and doing it for them more than for yourself. So the focus is not on you anymore; the focus is on your family or helping someone else.

Lizbeth knew that to stay healthy to promote a longer life, she needed to stay on a strict medication regimen. However, because she was so focused on being a good mother to her baby, she sometimes forgot her medication. Caring for herself became secondary to caring for her young daughter. While discussing her medication regimen, Lizbeth stated "I try to take them [medication] every day faithfully, but since she's been born all I think about is her and her needs, and it kind of makes me forget a little bit to take it".

Most women said they lived for their children and that their *children provided hope for their future*, living with an incurable, chronic disease. Being a mother provided meaning in their lives and was a role that many had looked forward to fulfilling. They took pride in being good mothers, making sure their children were well-cared for and

voicing a desire that their children had a bright future. However, they displayed *anguish at leaving them*, voicing concerns that they would not be here for their children's significant rites of passage, such as graduation from high school and/or college, weddings, and the birth of grandchildren. Katelyn, crying, said

When you're a mom, you always think about being there for your kid's prom or wedding day. It just hurts that sometimes it's like a possibility that I won't be there for it. And I think like that's what affects me the most is like not being there for my daughter.

Until the diagnosis of HIV-infection, the women did not have to think about their children's future without being in it; thus were now burdened with having to make plans for who would raise their children, in the event that they died. Alisa articulated

What am I going to do, what happens if I die, who's going to take care of my kids, who's going to, you know, make sure they have what they need? Who can provide for them the way I have, you know who? Who can give them the love and support and spiritual guidance that they need. And then you think, oh wow, okay snap out. I've got to fight through this, because no one can do that. Not their grandmother, not their dad, not anyone. No-one can give them the support that you can, you know. And so for a moment you have that moment I am going to die. I don't know when, I don't how...and you don't think about all the new advances that's out there than can help with HIV. You're not thinking about that stuff in the moment.

Interestingly, several women verbalized that as being HIV-positive, they had to *claim the disease*, thus they had to live with it and own it to care for themselves. Reandra

stated “I mean you can deny it in your own way, but still acknowledge it. But say I’m not claiming a disease; that was a lie. If I’m not claiming it then I’m denying the fact I have it”. Dutchess also stated “At the end of the day I know that this was not something that I asked for, but it’s mine, so I’m going to keep it. I’m not giving it away”. Yet, to feel protected, they had to keep their status hidden. Living with HIV was very burdensome.

Living with Multiple Layers of Betrayal

Living with multiple layers of betrayal expresses the women’s painful experiences of having their trust destroyed by family and significant others, and for most of the women, episodes of stigma and discrimination. Betrayal was not a word women used in the interviews, but accurately portrays the experiences of stigma, discrimination and altered relationships due to the disclosure of HIV. The occurrences of stigma and discrimination shamed the women into silence. Multiple layers of betrayal left the women humiliated and shaken, and chipped away at feelings of self-worth. One way to avoid possible future betrayal was to keep their status hidden, thus creating a world of aloneness.

Several of the women were *betrayed by their parents*, the individuals who were supposed to assure that their childhood was safe. Three women shared stories of abuse and neglect that occurred during their childhood. As an infant, Priscilla was repeatedly sexually abused by her mother’s male friends as a payment for her mother’s drugs. Her foster father also raped her repeatedly, resulting in Priscilla becoming pregnant when she was 11. Diana was sexually abused by her father. Although she does not remember the episodes of abuse, she is not comfortable around her father and avoids being alone with

him. Katelyn's Godfather, a trusted friend of the family, molested her over a period of six years. When talking about the abuse, she articulated that she believes it has impacted her self-worth, stating

I think it affected my self-esteem more than anything else... It just... like I didn't even feel worthy of anything other than, you know, being abused at that time in my life and it like took me a long time to even get past that. I think maybe I was a teenager when I finally started opening back up.

Nine of the women contracted HIV through sexual intercourse. Many of the male partners were unaware that they were HIV-positive and unknowingly passed it on to the women. Despite that, most women felt *a sense of betrayal, because they trusted their partners*. Dion stated

I was hurt and shocked, cause I didn't think that would happen because I was only with the one person for the past couple of years. So I didn't... well I asked him and he said he didn't feel like he had it, so he didn't really get checked on it.

Three of the women had unprotected sex with men who were aware of their diagnosis and for these women, the betrayal appeared to be much more significant. Both Alisa and Reandra were informed by people who knew that their partners were HIV-positive. Alisa, pregnant with her fourth child, requested to be tested. Reandra was never informed by her partner. She said

He never told me. I got sick in the hotel... I couldn't actually pinpoint it. Not too long after that I went and got tested and I found out. But before then I asked him about, cause someone had told me that it was a chance that he had it and I asked

him and [he] denied. Then when I found about about it, he was like nonchalant... you got it, I got it, like it's no big deal.

Reandra has forgiven him, but there is still a sense of anger that has not been resolved. Dutchess described her experience,

I got super drunk at a party, I guess I blacked out. I don't remember. I voluntarily had sex with this person. I remember the next morning, I woke up. I asked him what happened and he laughed... And I was always unsure about it... And then I later found out that he knew, had known since he was 14 and he's 26. And I'm like why would you purposely do that to me. He thought it was funny... Originally I was really angry because when I heard the numbers.... Why would you do that? I can't really say I'm still angry about it now. He has to deal with that part and I have to still figure out my side.

Several of the women also spoke about being physically and sexually abused by their partners, which impacted their ability to negotiate for safe sex. Priscilla was sure that if she could have negotiated to use a condom, she would not be HIV-positive. Unable to protect themselves, they were often put into unsafe situations that resulted in significant, life-changing events.

Although several of the women have shared positive stories of *family support*, *there have also been many episodes of betrayal*. Often the betrayal was subtle. If silence in the family has been the norm, family members may distance themselves from the person with HIV, as they do not know how to talk about it. Katelyn shared that her father believed he had not protected her, resulting in a shift in their relationship that left Katelyn feeling abandoned. Family members, uneducated about the modes of transmission, were

reluctant to touch or be touched by the women. It made the women feel uncomfortable and became another unwanted reminder of their diagnosis of HIV. Unfortunately more explicit demonstrations of betrayal were articulated in the stories. While Dutchess was hospitalized for an opportunistic infection, shortly after being diagnosed, her aunt posted her photograph, name, and HIV status on a social media website. Afterwards, she had several people in the community come up to her and tell her they had seen her photo and status online. Although Dutchess is still angry at her aunt, it has prompted her to educate people about HIV. Priscilla, talking about her siblings, stated

Before this... before I became HIV, they never tried to fight me, they always stood by my side when I needed them. Now since I've been HIV-positive, they always want to fight me and talk about me and stuff like that. And I'm like what is so different than back then when you always made sure I was okay and stood by my side. Now you all don't stand by my side, you all just let anything happen to me. If I died on the streets you all wouldn't even care. My brother said nope. He said I'll piss on your grave. So that just goes to show me your family ain't your family. They was faking all these years saying they stood by my side all these years.

Betrayal in the face of HIV has torn the fabric of familial relationships for some of the women. It has made them wary of whom they can trust, further leaving the women abandoned, isolated, and alone.

The church historically has been a safe place for African Americans. Several of the women continue to see it as a haven of support; however no-one in their congregation knew their HIV-status. One of the women, Diana, wanted more support from members

of the congregation as she continued to reconcile living with HIV, but was too scared of the members' reaction to her diagnosis to disclose to anyone. For two participants, *church was a place of betrayal*. Alisa, drawing upon her religion and church for strength, was told by the pastor and his wife that she would have to inform the congregation of her status. Concerned about their reaction and feeling betrayed, she chose not to attend church and is unsure if she will meet the same response at other congregations. Dutchess no longer attends church, believing it is full of hypocrites who judged her for being HIV-positive. No longer finding solace in the church, these women try to support their spirituality and religion through private endeavors.

However, for at least Alisa, there is now a void in her spirituality, as she is unable to participate in the church activities that were extremely important to her and supported her spiritual beliefs. Although many of the women have drawn upon their spiritual beliefs, as discussed further under the theme, *Living in the Everydayness of HIV*, one woman felt betrayed by God because her children were taken away and she had HIV. Mikayla shared that she used to attend church regularly, stating

But then I lost my kids, it's like I start feeling God didn't love me and once I start feeling that I turned that door and closed it... Sometimes I want to believe that God loves me, but sometimes like remember your kids ain't in your life.

The women experienced multiple episodes of *stigma and discrimination within the medical community*. Trusting that their healthcare team will provide optimal care, they felt betrayed by these episodes. This resulted in to reluctance to attend future appointments, as the women were fearful of the reactions of new providers. Diana,

seeking prenatal care, was informed at her first appointment that HIV-positive individuals should not have children and was asked to find another clinic. She said

I'm not no different than the next person; because it's like if I got cancer... then you going to treat me different, you understand? I think we all the same for real, we just got a disease that we living with.

Even though Katelyn's daughter was HIV-negative at birth, Katelyn overheard the NICU team refer to her daughter as the HIV baby. She stated

It really made me mad that they called her that... It was just like that's how they treat subjects... I didn't even say anything. It just kind of like bothered me so much, I just kind of wanted to go home.

Dutchess was in the emergency department for a procedure and shared her experience of HIV-related discrimination,

Well on my chart it says I'm a Ryan White patient. Any of the nurses down there, they know that Ryan White sponsors HIV treatment. I'm sitting in the room on the gurney and they didn't close the little glass door... There's a group of about six or seven nurses and I can see their feet. But one of the nurses goes, oh these people with HIV and AIDS kill me. They really need to just ship them all off to an island so they can keep breathing and infecting each other. And I'm like this is coming out of a nurse's mouth.

Dutchess was not only humiliated but felt dehumanized. She articulated that instead of health care providers and the public seeing HIV-positive individuals who have an illness that is affecting their body, they are made to feel they are lepers.

Within the medical community, the only place women felt safe was when they were working with their HIV-specialists. For several of the women though, even peer educators and case managers seemed judgmental and unsupportive of them. Natalie recently found out the peer educator with whom she had a connection committed suicide. Meeting with her new peer educator, she was put off by his attitude and believed that instead of listening to her, he was judging her. She is reluctant to continue a relationship with him. There was a sense among a few of the women that their case managers did not try to assure they had all of the requisite services to be optimizing their health. Trying to navigate a complex health system and with few financial and social resources, they felt betrayed by their case managers. Jacqueline did not feel like her case manager assisted her with obtaining necessary services, sharing “They just... they always come up with excuses here.... Saying well try it on your own first... I just feel like they’re not doing their job as a case manager”. Reandra, unemployed and struggling to make ends meet for her family, stated

I had a dental appointment one time and I didn’t have no money to pay for it, so the lady... said she will write me a referral and she never did. So I was like, well I really, really have to go to the dentist to have my tooth pulled, it’s an emergency, so I just said, well I’ll just call you when I’m there then that way you can fax it to them or, you know, do whatever you do, she still never did. That’s on my credit report right now.

Within the public sphere of their lives, the women were concerned about stigma or discrimination. Alisa, during our interview, handed me the pen after signing the

consent form and shared that she was not sure I would take back the pen after she had touched it.

Living in the Everydayness of HIV-Infection

Living in the everydayness of HIV-infection describes and interprets the daily experiences of not only the women, but also their families, as they were all challenged to live a normal life in the context of HIV. For many of the women, HIV has reframed their lives. All of the women described a life that was now different upon receiving the diagnosis of HIV infection. Many women stated that they no longer felt normal; living with HIV was not normal. Katelyn said

When I look up in the morning and I look in the mirror, I try not to look at myself like, you know, you have HIV. I don't try at all, cause if I did, I probably wouldn't be mentally okay.

Mikayla stated "I wish I could erase the fact of being HIV-positive. Because it's like I feel disgusted, you know what I mean? Really just disgusted with life, myself". It was as if there was a split between their cognitive and emotional understanding about HIV. Whereas the women understood that HIV was another chronic illness, they also emotionally felt very diseased. As such, their feelings of self-worth were altered. Already filling multiple roles of mother, partner, sister, and daughter, the women are now coping with *depression, caring for themselves in new ways, relinquishing control to God, and leaning on their families for support.*

All women expressed becoming depressed upon learning their diagnosis. Katelyn, when she received the diagnosis, said

I went into an intense, intense depression... I just didn't know what to do with myself... I didn't even go outside ever, like I felt like everybody could see, I guess, what was wrong with me and, I just remember that day and it was rough.

Several contemplated suicide. Mikayla, lacking education about HIV transmission during pregnancy, thought she would transmit the virus to her unborn baby and considered suicide as the only viable option. Her boyfriend at the time reminded her that she had to live for the baby. Diana was concerned that she would not go to heaven if she committed suicide; and as well, she had a new nephew and wanted to be a part of his life. Although the women did not act upon their thoughts, it is important to understand the intensity of the depression that they experienced.

For all of them, the *depression* has remained pervasive. Alisa and Dutchess were not only dealing with depression, but had also experienced panic attacks. Alisa stated "I have panic attacks so bad that I don't know if I'm coming or going. I wonder sometimes if they're going to take my [driver's] license away because I get so filled with panic and I can't tell where I'm going". Dutchess said "Like I didn't know how I was going to make it through. I was forcing myself to put on like a really brave front, but I didn't know exactly how I was going to make it through". Being so isolated from the world, they were unable to articulate their *depression* and frequently keep it hidden. That the depression is related to HIV is only one reason they keep it hidden; several were concerned that they would be committed to an inpatient psychiatric unit. Jacqueline, when discussing not wanting to take anti-depressants, shared

I think they were trying to get me on that and they were trying to see how crazy...
I'm not at that stage of craziness and I think they were trying to get to that point

and trying to get me committed to a hospital and stuff and that's why I stopped seeing her [therapist].

The women were resistant to taking medications, particularly if they were on ART therapy, as anti-depressants would be yet another medication to add to their regimen. Only two women were regularly working with a counselor, and several women were considering counseling, but had not made plans to attain that goal. For a few of the women, working with a counselor would force them to talk about being HIV-positive women; talking about it made them more depressed.

The women realized that *taking care of themselves* was important to their overall health. Maintaining physical health was confounded by disorders developed as a result of HIV or its treatment. Alisa shared "People don't realize, when you have HIV, you have all kinds of mental issues that come along with it. You have all these health conditions that come along with it, because since having HIV, you have high cholesterol now". Disease management became more complicated with multiple medication regimens, appointments, and staying educated. Maintaining a close relationship with their providers and understanding the disease process was important for their physical health. Dutchess stated

If I feel like there's something seriously wrong, I'm immediately at the doctor; I'm on the phone, you know with my prevention counselors or I'm on the phone with the specialist... just trying to figure out what it is that I'm feeling. If there's something that I need to be on the lookout for or alarmed about.

However attending appointments could become challenging, as for many women, regular transportation was an issue. Reandra stated that her appointments were scheduled

every three months, however “Most of the times I can’t make it cause I don’t have a ride”. With CD4 counts that were at appropriate levels, approximately half of the women were not routinely on ART therapy. During their pregnancies, women were on ART to minimize transmission to their infants. Several women on ART were caring for infants and young children; thus maintaining a strict regimen was difficult. They tried to develop reminders, such as setting an alarm or keeping a medication journal.

The women talked about trying to maintain a healthy diet and take vitamins to optimize overall health. Their economic situation was sometimes prohibitive to achieving a healthy diet, both in terms of finances for transportation to supermarkets that provided quality produce and meats and then being able to afford such items. Most women did not exercise regularly for multiple reasons, such as depression related lack of energy, family caregiving, lacking money or transportation to go to a gym or exercise classes, or living in an area where walking was not safe (i.e. busy street without sidewalks). Few women used methods such as meditation or journaling to alleviate stress. However, Dutchess developed a creative way to address stressful situations. She stated

I keep multiple journals around the house... It’s a way for me to express my emotions without verbalizing, you know. I’m the type of person, if I’m upset and I’m not able to clearly write out what I’m upset about, I’m going to go off about everything... If I’m doing a short story, I’m trying to create a character and walk them through what’s bothering me. See if I can maneuver this character through all these situations and problems, then I know I can maneuver myself too.

Most of the women sought educational offerings, including support groups and women's retreats to assure they were knowledgeable about their illness and to garner support from one another. Dutchess stated

Currently I take a class. I love the class. I love the girls that I'm in the class with. I'm the youngest in the group and I, of course, am one of the last to be diagnosed and they've been so helpful as far as being supportive of me.

When asked what nurses could do to better support women, Natalie stated

I think I like the fact that when HIV women do get together and you are more comfortable, you can bond more with people that experience the same as you. And cause they have like somewhat of an understanding of what you're going through and you can hear their story and how they deal with it and they can help you out. So like group meetings are girl support.

Again, transportation was an issue for quite a few of the women, as they had to rely on public transportation or family and friends. Despite the desire of many women to participate in support groups, depending on the time and location, they may not be able to continually participate. Not all of the women desired a network of HIV-positive women for support. Diana stated "I can't talk to everybody. Somebody one-on-one I would talk to, like you".

Spirituality and religion were a very important part of most women's lives.

Although several did not believe that their spiritual views changed after their diagnosis, a few believed that the diagnosis of HIV prompted them to develop a stronger relationship with God. Alisa stated

If you've never really thought about God and being on the spiritual level, when you become HIV positive, it's almost like a person that's going to jail for the first time, you find spirituality and becomes the biggest part of you and sometimes people don't realize that you saying because I am so spiritual and I believe in God so much that nothing happens unless God allows it to, and therefore He wants us to lean on Him, to depend on Him, to need Him. And in that respect, when you become HIV-positive... you tend to turn to where you probably should have been in the beginning. So I become a big part of God.

With the exception of one woman who felt that God had turned against her, the women found *strength in prayer* and *reading the Bible*. This was particularly helpful to cope with their depression. Several women attended bible study and church services, but again, were careful to shield their diagnosis from the congregation. Diana stated

I don't tell... cause I don't like whenever I tell the people my business, but I mean since they know... I mean they know I'm going through something... They are supportive. I could like just talk to somebody that's close like in the church family or something, then I think they would be more supportive, instead of letting the whole church know; that's just none of they business.

Disclosing to their families was a significant event, as the women were not sure how they would react. Diana shared

It felt embarrassed for real, because I've never thought I have it, so me telling them... I'm HIV positive is like... they looking at me like, wait... I'm like, yeah, I've got HIV. They looking at me like well we not going to look at you no different cause we're family.

Katelyn also shared

You know, some people love you. I think that's kind of how you determine who your real friends and family are. It's like if they love you outside of it, you know, that's good, but if they didn't then what can you do about it.

Two participants, both still with the partners who infected them, engage with their partners as a way to support one another. For Lizbeth, this is really her safe place, as her family is unaware of her diagnosis. Dion has disclosed to her family, and draws upon their support to help her cope. Since her diagnosis, she believes that they spend more time together and are closer as a family. Betsey's family helped her manage HIV. She stated

My kids, my husband, they all make sure; hey you take your meds today? They all know my regimen; they know my schedule; they know what my pills look like, so they're able to help get that medicine together. If you have a family, it makes life a whole lot easier.

Dutchess, when talking about her adolescent son helping to care for her, said

He reminded me that even when I don't feel like it, I'm still a mother, I still have to get up and do what I gotta do to make sure he's taken care of... And what did he need to be able to help me...And I think if he wasn't around, there is a great chance that I would have just kind of given up on it.

As a result of her mother's diagnosis, Betsey's oldest daughter wants to become a public speaker about HIV education and families living with HIV. The everydayness of living with HIV articulates that HIV impacts everyone in the family every day.

Additionally, the idea of *stigma is significant in the everyday formation of everydayness of relationships*. When going through the informed consent process, Betsey was unsure that I would take the pen from her. I was quite taken aback, as it would never occur to me that she would think I would be afraid to touch the pen after she had used it.

Chapter 5: Discussion and Conclusion

Discussion

This chapter includes a discussion of the findings, including integration of Heidegger and Van Manen's philosophical concepts, a comparison of the findings to other relevant literature, limitations of the study, and implications for education, practice, policy, and research. Eleven women shared their unique stories of living with HIV. I, as the researcher, transiently entered into their worlds for a glimpse, a snapshot, of their everyday life, living with HIV. The themes that emerged from the stories cannot convey the comprehensive realities of life unique to each of the women. Therefore, it is important to understand that the pattern and themes, while interpreting the idea that HIV has penetrated the many facets of their lives, is not exclusive in the interpretation of how the women live daily.

There were three research questions posed in this study: 1) What is the lived experience of young African American HIV-positive women; 2) How do young African American women living with HIV infection define the meaning of spirituality in the lived experience of being HIV-infected; and 3) How do young African American women living with HIV infection define and practice self-care behaviors in the context of HIV. The pattern, *Infected Lives*, and the four themes, *Living Alone with HIV*, *Living with Unresolved Conflicts*, *Living with Multiple Layers of Betrayal*, and *Living in the Everydayness of HIV* answered the research question, What is the lived experience of young African American HIV-positive women. *Living in the Everydayness of HIV* provided information to answer the two research questions, How do young African American women define the meaning of spirituality in the lived experience of being HIV-

infected and How do young African American women living with HIV-infection define and practice self-care behaviors in the context of HIV.

The women were living with HIV, a disease that was profound enough within the diagnosis; however possibly more profound was the pattern of *Infected Lives*. Gadamer states

Sickness and loss of equilibrium do not merely represent a medical-biological state of affairs, but also a life-historical and social process. The sick person is no longer simply identical with the person he or she was before. For the sick individual 'falls out' of things, has already fallen out of their normal place in life (1996, pg. 42).

Being diagnosed with a chronic illness or a life-threatening illness is life-changing. Individuals living with a life-threatening and all-encompassing illness, such as HIV, are forced to contemplate a new life that is now physically measured by CD4 counts, viral loads, and possibly adherence to ART. Mentally, psychologically, spiritually, and socially, they are challenged to find the equilibrium between illness and health, where HIV does not dominate their overall health. Participants were devastated upon learning that they were HIV-positive, often resulting in a deep depression from which most have not recovered. HIV has tainted their lives. Within their immediate world they daily dealt with loneliness, shame, and isolation, while caring for themselves and their families. Within their wider worlds of family, friends, healthcare providers, schools, social services, and community, they often faced judgment, objectification, betrayal, devaluation, and rejection, while again trying to care for themselves and their families and attempt to live a normal life. The women were forced to consider new, unwanted

possibilities, including death as a young adult or missing their children's significant life events. Despite the hope that their children gave them, the women overall were resigned to a life that centered on a chronic, life-threatening illness. These important life events are the webs of significance that inform the stories of the women's everyday lives.

Heidegger uses the term *thrownness* to articulate the essential determinant of humans' existence initially as born into an already existing world and then continually thrown into worlds not of their choosing (1962). This study was to learn about the experiences of these women thrown into the world of HIV. Consequently, their stories reflect a timeline beginning with their infection up to the present. Questions did not probe into upbringing although in several cases the women freely discussed their childhoods and adolescence. When I speak of Heidegger's term *thrownness* or being thrown into a world, I mean it in the sense that these women have been cast into a world of disease within a larger already existing world, and for some, a world infected by poverty, abuse, and dysfunctional familial relationships. Being thrown into the world of HIV situates the women in a world of *Living alone with HIV, Living with Multiple Layers of Betrayal, Living with Unresolved Conflicts, and Living in the Everydayness of HIV*. Although it has closed off possibilities for a "normal" life and future, discussed by several of the women, it has also opened new possibilities. One of the participants has created a new future, desiring to work with other individuals living with HIV.

Being thrown into a world of HIV, several of the women conveyed that they *now owned their illness*. They owned it and would not deny it, as denying it prevented them from caring for themselves. This idea of owning their illness is in alignment with Heidegger's idea of thinking of our potentialities through a fundamental anxiety about

being authentic in one's life (1962). The owning of their disease spoke to a desire to be honest and authentic in appraisal of their lives, even if they could not be honest in relationships with family, friends, and community due to valid concern about the possibilities of stigma.

Although *Infected Lives* conveys that HIV has invaded all aspects of the women's worlds, it also does express the impact of HIV on their lived body. Through the interpretation of Heidegger's philosophy, our body can be seen as a use item. It functions very well as the most immediate *ready-at-hand* tool that we use to accomplish everyday tasks. It functions *ready-to-hand* because we do not think about it when we are cooking dinner or when we are cleaning the house. It is only when we are sick that we see our body *present-at-hand* and realize we do not have the strength to attend to these everyday tasks. The women disclosed in their stories the understanding of their body as *present-at-hand*. They had a stable disease; however, in several situations, the women felt fatigued and had to frequently rest and for some, the medication side effects were often disabling. The disease and the medications have forced them to look at their bodies in a new light from doing what they want and need to do without thought to being more conscious of their bodies.

Seeing a change in their physical bodies was not unique to the women in this study. In a study of rural women living with HIV, participants expressed that they saw a physical change in their appearance, which made them feel more noticeable. They also conveyed concern about the medication side effects and other physical ailments as a result of their illness (Phillips, Moneyham, Thomas, & Vyavaharkar, 2011). Shandor Miles and colleagues in their study of African American mothers living with HIV found

that the women reported problems with activities of daily living, work-related activities, and multiple physical symptoms (2001). Attending to or because of the physical symptoms related to their illness has disrupted the normalcy within the lives of women who are HIV-seropositive; they cannot assume that they will be able to perform in the same way as prior to the diagnosis.

Being diagnosed with HIV shattered the world in which the women had been living and created a new world of *Living Alone with HIV*. Even for women who had support from their families or significant others, they felt like no-one could completely understand their everyday experiences living with HIV. Even with supportive families, several participants shared the idea of being separated from everyone. This idea of aloneness is similar to the concept of loneliness discussed by Shandor Miles and colleagues (2010). In their qualitative research of African American men and women living with HIV, the participants experienced profound loneliness, as a result of having few individuals with whom they could share their feelings.

Within the theme of *Living with Unresolved Conflicts* was an idea that the women must *protect themselves* from the public to avoid stigma, subsequently *becoming isolated*. Feist-Price and Brown postulate that the hidden lives of African American women stems from stigma associated with the diagnosis of HIV, as a result of the societal relationship of HIV with immoral behaviors, such as promiscuity (2008). The participants in the present study protected themselves from stigma through hiding their disease, within familial relationships and/or social systems. This idea is supported by other current literature. Phillips and colleagues found a similar theme in their study (2011). Participants, concerned about stigma, physically hid from the community, such as going

to the grocery store late at night. In another study, participants reported living in secrecy, concerned about how they would be treated by others (Shandor Miles, Roman Isler, Banks, & Corbie-Smith, 2010). Enriquez and colleagues in a study of Latina women living with HIV (2010), discovered the same theme of isolation. Having no-one to talk to, the women were grateful for the opportunity to participate in their study, as it was the first time for many to talk about their illness. In these previous studies, the idea of hidden and isolation were negative experiences.

In the current study the idea of shielding oneself was seen as a positive way to protect self. Van Manen in discussing *spatiality*, or lived space, states that home is a secure sanctity where individuals feel protected. He says “Home is where we can *be* what *we are*” (1990, pg. 102). For many of the women in this study, home was their sanctity, where they felt protected and they could be authentic in living with HIV. One participant rarely left her house, believing that it was her only protection from the world. However, by shielding themselves from stigma, they had self-perpetuated a world of isolation, closed off from their community. The experiences of isolation are not specific to African American women living with HIV, as evidenced by the findings in the study of African American men and women, and the study of Latina women.

Within the theme, *Living with Unresolved Conflicts*, was the idea that the women’s *children gave them hope for the future, but they also expressed anguish at the idea of leaving them* early through their death. Several women expressed that their children gave them a reason to live. The role of mother is highly valued in African American culture (Shambley-Ebron & Boyce, 2006b). Although the concept of mothering within the context of living with HIV was not central to the present study, all

women had children. Being a mother gave joy and they took their role as a mother very seriously. This is in alignment with findings in Shambley-Ebron and Boyle's ethnographic study of the mothering experiences of HIV-positive African American women (2006b). The women considered caring for their children as a top priority. As young women, the participants had not considered their death prior to the diagnosis of HIV. Van Manen's ideas of *lived time* is the temporal way we are in the world (1990). The significant event of being diagnosed with HIV for many of the women occurred in the developmental stage of searching and finding their unique identity. Prior to diagnosis, these young women had an entire life ahead of them. How they report planning for the future now looks quite different.

In everyday life, it is common to set goals for the future, typically without doubting that one's life will progress to old age. Yet for African American women diagnosed with HIV, many of whom are between the ages of 20 and 39, future planning shifts drastically (Feist-Price & Brown Wright, 2008, pg. 32).

The women were concerned about missing their children's important life events and were also concerned about their children after they were gone. Originally contemplating a future with possibilities, the women believed that they had to re-adjust their ideas of the future, now attending to more concrete details such as who would care for their children in the event that they died. Although the women did not report thinking about death daily, they had certainly thought about it, and for several, death loomed in their more immediate future, despite the stability of their illness. In a qualitative study of mothers living with HIV, participants were burdened by an unknown future for themselves and their children (Nelms, 2005). Although they did not dwell daily on their deaths, they

were forced to think about their futures differently. In their study, Shambley-Ebron and Boyle described a sub-theme of preparing the children in their study (2006b). Women had to prepare their children for the possibility of their deaths and make decisions about who would care for their children if they died. Despite the hope children provide mothers living with HIV for the future, the women also experience anguish and anxiety as they contemplated the potential reality they may not live as long as they had originally planned.

External strength with internal fragility was a concept found within the theme, *Living with Unresolved Conflicts*. Although the women displayed external strength, there was an internal vulnerability. This is not to suggest that they were weak; they were not at all. Jones and Shorter-Gooden posit that African American women are seen by the public as “impervious to life’s most challenging events and circumstances” (2003, pg. 11). Subsequently, it is difficult for them to accept and display their vulnerabilities. This captures the essence of women who participated in the current study. They had many roles to manage and myriad complex issues as a result of HIV that influenced their vulnerabilities; however, they tried to keep their vulnerability hidden behind a wall of strength.

Shambley-Ebron and Boyle (2006a) describe the challenges of African American mother’s living with HIV within the context of being strong women, which is different from the findings in this study. In the present study, although outwardly strong, internally there was a lot of vulnerability and fragility. However, they mention that the participants faced many of the same challenges as women in the present study, including being African American, female and living with a chronic, life-threatening illness. They

further caution that the stereotype of African American women being “super-strong”, as discussed by Jones and Shorter-Gooden, is a threat to African Americans health. It is important to recognize that African American women living with HIV often do face many challenges, but may be unwilling to express such challenges and the vulnerabilities that result from these challenges.

Many of the women in the present study expressed a *tension between caring for themselves and caring for their families*, supporting the theme, *Living with Unresolved Conflicts*. Although they recognized the importance of attending to their own health, they were the primary caregivers for their children, thus care for self at times became secondary to caring for children. This was particularly true for the many women with infants and young children. In comparing the women’s experiences, I found that women who had support from their families, whether through acceptance of the diagnosis, closer proximity of families, or older children who knew their mother’s status, seemed to be able to better negotiate the tension between care of self and care of families. Researchers have found that one of the barriers to self-care among African American women living with HIV was caregiver responsibilities (Tufts, Wessell, & Kearney, 2010). Although the women in their study discussed caregiving roles in terms of caring for parents or significant others, compared to the idea of caring for children in the present study, the idea of juggling multiple caregiving roles, both of self and other family members is a concern for African American women living with HIV, as it can have a negative impact on the overall health of these women.

Living with Multiple Layers of Betrayal speaks to the *stigma and acts of discrimination* that the participants experienced as a result of their disclosure to family,

friends, and health care providers. Van Manen describes *relationality*, also called the lived other, as

The lived relation we maintain with others in the interpersonal space that we share with them. As we meet the other, we approach the other in a corporeal way: through a handshake or by gaining an impression of the other in the way that he or she is physically present to us (1990, pg. 104).

The relationality of these women in their world of HIV is that they have experienced shunning, discrimination, and derogatory comments. The women's *relationality with others-in-the-world* has become profoundly altered by HIV. One participant conveyed this in our interview, being unsure I would take back the pen after she had used it. Our relational space was initially influenced by her concern that I would display stigma. Parker and Aggleton describe stigma as "understood as a negative attribute, is mapped onto people, who in turn, by virtue of their difference, are understood to be negatively valued in society" (2003, pg. 14). This idea of stigma supports the altered relationality in the women's worlds as shaped not by them but by their interpersonal and social systems.

Stigma and discrimination are certainly not unique to the women who participated in this study. This finding is congruent with several other studies exploring the experiences of African American women living with HIV. Phillips and colleagues discovered that women living with HIV experienced stigma in both interpersonal and social systems (2011). Shandor Miles, Roman Isler and colleagues interviewed African Americans living with HIV as well as community leaders and HIV service providers (2010). Participants described communities that avoided and denied HIV as an issue in

their communities, leading to negative views of HIV. They said that community members were fearful of contracting HIV, thus avoided individuals who were HIV-positive. One participant in their study discussed how individuals with HIV were treated like they had leprosy. In the present study, several participants shared similar thoughts, with one participant actually using this term, “the public view HIV-positive individuals as lepers”.

In both Shandor Miles’ study and the present study, participants described episodes of stigma and discrimination within the healthcare setting. Vyavyaharkar, Moneyham, and Corwin also found in their study on health care utilization among rural HIV-positive African American women (2011) that the participants had experienced stigma and discrimination within the health care setting, which were significant barriers to utilizing resources and services. Shambley-Ebron and Boyle found during data collection that the actions of the white healthcare providers toward African American women displayed stigma and negativity (2006a). If individuals living with HIV experience *stigma and discrimination* in the health care setting, it may prevent them from accessing services, as found in Vyavyaharkar’ study. Stigma and discrimination can contribute to harmful power differentials in the patient-provider relationship that could negatively influence the overall health of individuals living with HIV, by discouraging patients from seeking needed health services. Finally, if individuals living with HIV experience stigma from trained and seemingly educated health care providers, it may further increase their concern of perceived stigma within their communities, made up of individuals who may not be as educated in HIV.

In a longitudinal study of HIV-infected and non-infected African American women, researchers found that HIV-infected women perceived significantly higher levels of HIV-related stigma than did the non-infected women (Jordon Clark, Linder, Armistead, & Austin, 2004). As level of stigma increased, the women's level of disclosure decreased, and psychological functioning also decreased. They also found that women who had disclosed to a greater number of people scored higher on perceived stigma and lower on psychological functioning. Although stigma, disclosure, and psychological functioning were not quantitatively measured in the present study, the women's stories told of experiences of stigma from families and friends, often disrupting their relationships. They were more isolated and had less coping resources. Stigma and discrimination are very complex issues within the realm of HIV/AIDS and have been extensively addressed in the literature. The findings from the current study lend support to previous literature.

All of the women who participated in this study described *chronic depression* that commenced upon learning their diagnosis of HIV and had become a facet of the *Everydayness of Living with HIV*. Depression impacted their ability to conduct their daily lives, whether it was engaging in care for self or care for their children. Jones and Shorter-Gooden (2003) suggest that depression is a complex issue for African American women and that they often remain silent about their depression for several reasons. The idea of depression is at odds with the cultural norms of being capable and strong. In addition to a common perspective in the African American community that depression is a personal weakness, professional treatment is not welcomed (Jones & Shorter-Gooden, 2003). Overall, the women were not treating the depression, reluctant to take

medications or work with a therapist. One participant said her healthcare providers never ask her about it and she never mentions it. In a recent study evaluating HIV-disclosure, social support and depression among African American women living with HIV (Vyavaharkar, Moneyham, Corwin, Tavakoli, Saunders, & Annang, 2011), researchers found that despite scoring high on the depression scale, approximately 40% of participants had never been diagnosed with depression; of the participants who had been diagnosed, more than half were not receiving treatment.

The concerns about *depression* within the present study are congruent with the ideas articulated by Jones and Shorter-Gooden. Several women in this study were worried about healthcare providers believing them to be unstable and requiring inpatient care, therefore unable to continue to take care of their children. Rather than formally address their depression with medications or counseling, they tried to find other ways, such as prayer and other spiritual practices. Again, using spirituality as a coping mechanism was discussed by Jones and Shorter-Gooden, as a culturally appropriate method to cope with depression within the African American culture.

Depression as a result of learning the diagnosis of HIV is certainly not unique to the participants in this study. In a study of the social context of rural women living with HIV, Phillips, Moneyham, Thomas, and Vyavaharkar found that the participants experienced loss and depression (2011). For several of the participants in their study, the depression was so severe that they contemplated suicide. Although several women discussed suicide in the present study, they had suicidal thoughts immediately after they learned their diagnosis. One participant reported having suicidal thoughts between our first and second interviews, articulating that she could not find meaning in her life. She

denied suicidal thoughts at the time of our interview, but promised she would contact her case manager to coordinate psychiatric services. She was experiencing significant losses, in alignment with participants in Phillips and colleagues study. Shandor Miles, Roman Isler and colleagues in their study of African Americans living with HIV found that the participants experienced socioemotional suffering (2010). They had to keep their emotional distress of living with HIV hidden. Women in this study also alluded to having to keep their depression hidden. Hiding their illness and their depression may have fostered an even greater sense of aloneness.

Defining and describing *self-care activities* was one of the research questions in the present study. However, little information was provided by the participants to address this question, as they expressed more important information about living with HIV, as discussed earlier in the discussion. Interestingly, when a few of the participants were asked to describe how they took care of themselves, they spoke of engaging in activities of daily living, such as attending to their hygiene. A broader explanation of *self-care* was necessary to garner information about how they took care of themselves to support their physical, mental, and spiritual health. The women did employ activities of *self-care* to support their health. Although several participants were limited by practical considerations, such as transportation and economic situations, participants in this study engaged in self-care by attending appointments, working with their case managers to make sure they had the necessary medical and social support to manage their illness, and maintaining a healthy diet.

These findings are supported by a previous study of *self-care activities* among African American women living with HIV (Tufts, Wessell, & Kearney, 2010). In their

qualitative study, the participants also articulated that they maintained health care provider appointments, medication regimens, and trying to adhere to a healthy diet. Similar to the experiences of women in the present study, participants had to re-evaluate their relationship between caring for self and caring for others, which was a transition that took time from diagnosis to the present.

The impracticalities of *self-care* voiced by several of the women in the present study were also articulated by participants in Shambley-Ebron and Boyce's study of mothers living with HIV. In their study, participants voiced frustration that they could not fully engage in *self-care* due to conflicting financial concerns, such as paying for their utilities or paying for fresh produce and assuring they had three healthy meals a day. Financial constraints for several women in the present study required negotiating between supporting themselves and their children and optimizing their health, for example buying the best produce at expensive grocery stores. Health care practitioners need to be culturally sensitive to the constraints placed on individuals living with HIV as they attempt to fully engage in *self-care practices*. Asking them to exercise and eat a healthy diet may simply not be feasible within the context of poverty.

Participants also described their *spiritual practices* as *self-care* within the *Everydayness of Living with HIV*. This seemed to be the strongest form of *self-care* for the women, as it helped in coping with emotional and spiritual distress. Only two women in the present study did not have strong spiritual or religious beliefs. The other nine regularly engaged in spiritual/religious practices, particularly when they were depressed or stressed. During these times, talking to God or reading the Bible uplifted them and gave them strength. These findings are similar to the findings in studies of African

American HIV-positive women. Polzer Casarez and Shandor Miles (2008) discovered that a relationship with God increased hope and reduced distress. Wright (2003) also found that the African American women living with HIV had a deep faith in God. Most of the women experienced a significant increase in spiritual beliefs after their diagnosis of HIV, which is different from experiences of most of the women in the present study. It may be that her sample was older, possibly influencing maturity and reflection.

Although *spirituality* was important for participants in the present study, *stigma and discrimination* within religious organizations were components of the theme, *Living with Multiple Layers of Betrayal*. Several women believed that they were not welcomed at their church once the pastor or congregation found out their diagnosis. This was a significant issue for the participants who had experienced stigma. Women who continued to attend religious services made sure that their congregation did not know their HIV status as a way to protect themselves from unwanted scrutiny and gossip, which were not unfounded concerns.

Muturi and An (2010) explored HIV stigma and religious beliefs among African American women. Interestingly, the more religious the women were, the more likely they would be to display stigma toward individuals living with HIV. In their study, the women's answers to open-ended questions suggested that it was the individual's fault for contracting HIV because of living a sinful life. The researchers expressed concern that through the teachings in religious organizations, HIV stigma may be reinforced. The African American faith based community historically has not responded to the HIV epidemic because of the negative religious attitudes associated with the transmission of HIV (Griffith, Pichon, Campbell, & Ober Allen, 2010). Recognizing that HIV is a

serious health issue in the African American community, the attitudes of the faith-based community are changing (Wooster, EShel, Moore, et al, 2011).

Given the negative social environment in many faith based communities, it is not surprising that participants would be concerned and fearful about congregation members' reactions to their HIV status. In a research study exploring spirituality among African American women living with HIV (Morse, Morse, Klebba et al, 2000; Woodard, 2002), participants discussed different forms of spiritual practices including private and public. Public practices included attend church services, bible study, and other church sponsored events. In Morse and colleagues' study that compared HIV-infected and non-infected women, HIV-infected women were less likely to participate in public practices. Unable to attend church functions due to concern of stigma leaves a void in women's spiritual lives that may not be filled by other spiritual practices.

Family support and self-care activities were important considerations within the theme, *Living in the Everydayness of HIV*. The support of family, defined by the participants as support provided by their significant others, parents, and siblings, is an important finding in the present study. For several of the women, the support of their families was instrumental to their ability to cope with living with a chronic, life-threatening disease. The sub-themes explicated from the stories spoke to the increased ability to cope with living with HIV and self-promoting care activities among women who had strong support systems within their defined family. Vyaavaharkar and colleagues (2011) found an inverse relationship between depression and social support. With higher levels of social support, the participants reported lower levels of depression. This finding resonates with the experiences shared by women in the present study. All

women had reported depression, but women who had close family bonds and family support seemed overall better able to cope with living with HIV.

Limitations

There were several limitations in this study. The researchers relied on participants' self-report as the data used to formulate the themes and patterns. I interviewed eight women twice, with the time between interviews spanning from two to six months. For several of the participants, during this time, there was a significant change in how they perceived their relationships, whether with family, sexual partners, or other people with whom they interacted in their everyday world, thus certain biases or feelings regarding these relationships may have influenced the information they shared. However, their perceptions of their lives are truly their reality; therefore that was how I approached developing the stories and subsequently the themes and pattern. I provided monetary compensation for each interview, so motivation for participation in the study may have been related to compensation rather than the desire to share their experiences living with HIV, which could have influenced the depth and quality of information provided.

As a novice researcher in conducting Heideggerian phenomenological research, the pattern and themes could be read as superficial and descriptive. To overcome this limitation, I worked closely with one of the research team members, who is an expert in qualitative research and interpretive phenomenology, to write the stories and develop the pattern and themes. In addition, the pattern and themes were validated through member checking. I only interviewed eight women twice, and three women only once. I only captured a small part of their lives. Ideally, a third and even fourth interview would have

been helpful to learn about their experiences growing up, more about their families, and children. All of the participants were recruited from infectious disease clinics, implying that the women were engaged in care. The findings of this study may not be congruent with the experiences of young African American women who are not actively in care. Because the women lived in or near a metropolitan setting, the findings may not be transferable to rural populations of African American HIV-infected women living in rural settings. Additionally, most of the women who participated in this study lived in a lower socioeconomic setting. Thus the findings may not be transferrable to African American HIV-infected women who are living in a higher socioeconomic setting.

Implications

Implications for Education

K-12 Education

Given that HIV-related stigma is still common among the general public, it is important that education about HIV/AIDS begins early in the educational process of children and adolescents. Many HIV and sexually transmitted infection programs are used in public and private education settings focused on prevention. I am a co-director for the Dramatic AIDS Education Project, an interactive educational program that reaches over 8000 students in the metropolitan area every year. While this program imparts important information about HIV and STDs, it does not address the stigma that is attached to the diagnosis of HIV. We are planning to conduct a study with focus groups of adolescents to evaluate the effectiveness of the program in terms of HIV prevention. I think it will be important to include questions about HIV-related stigma as part of our evaluation. Reviewing the literature about HIV education, I found comprehensive

education about HIV and STD prevention, but could not find any programs that specifically addressed stigma and discrimination as an important component of HIV. The issues of stigma and discrimination need to be explicit in the discussion about HIV.

Health Professions Education

Health professions students should understand disease and illness within the context of the everyday lives of their future clients. Inter-professional seminars that include HIV-seropositive client panels could facilitate discussions about the emotional, mental, and social complexities of living with HIV to further develop culturally congruent interventions that addressed all necessary components of their health. Ironside and colleagues (2003) evaluated the co-creation of the meaning of chronic illness with individuals who were living with a chronic illness and graduate nursing students. With clients describing their experiences of living with a chronic illness, the nursing students were introduced to the clients' everydayness in the context of their disease that expanded the students' understanding beyond the textbook picture of the diagnosis, medical treatment, and nursing interventions. This type of innovative pedagogy invites the health professions student to think beyond the diagnosis and begin to understand the lived experience of individuals who have a chronic disease. An inter-professional forum would assure that students addressed every aspect of the complexities of living with HIV. HIV-seropositive clients in attendance at these forums would assure that comprehensive education was provided, including key aspects of their lives, such as not having transportation or living in transitional housing that complicate their lives, in order to develop and deliver care that truly is patient-centered in the context of their illness.

African American women living with HIV have very complex lives, as do many other individuals living with HIV. Health professions students should learn to conduct a comprehensive assessment that addresses physical, mental, spiritual, and social health. African American women living with HIV often care for themselves using spiritual practices. Students need to be comfortable talking about spirituality and integrate spiritual practices into their patients' plan of care, if they find through their assessment that such practices are important for their patients. Spirituality as a concept is taught in the third semester in our baccalaureate curriculum. Because it is not integrated across the curriculum, I am not sure how comfortable students are addressing spirituality and religion with their patients. Spirituality, as an important facet of our beings, should have more than one class period devoted to it. Culture and cultural competency should be provided across the spectrum of nursing and health professions curricula. Findings from the present study reinforce the significant influence of cultural norms on health care issues. Students need to be aware of how culture frames health and illness and learn how to look at the client's life through the lens of the individual rather than their nursing lens to develop a broader understanding and sensitivity toward their clients.

Health Professionals' Life-Long Learning

Given that multiple women in this study experienced multiple episodes of HIV-related stigma within the health care setting, it seems that there is a need for comprehensive HIV education that not only includes the pathology, medication therapy and services, but the everyday experiences of individuals living with HIV. Interactive simulation or interactive online modules that were created by HIV specialists and patients could be offered as continuing education opportunities. Included in the sessions would

be pre- and post-tests that included perceptions of individuals living with HIV for evaluation of stigma and if it was present, had it reduced. Cultural competency is never fully achieved, but is always an ongoing process. Culture and cultural competency as outlined for health professions students should be considered with health professionals. Yearly courses in culturally competent care should be mandatory or at least encouraged so that health professionals are, again addressing their clients' health concerns through the clients' lens, rather than theirs.

Community/Public Education

Unfortunately, the words HIV and AIDS seem to evoke a negative image within the public sphere, forcing individuals living with HIV to hide their diagnosis. One of the three goals developed at the 30th AIDS World Day is Zero Discrimination. We are called to address the discrimination and stigma that continues to invade the lives of individuals living with HIV. As health care providers who frequently educate the public, nurses should be at the forefront of achieving this goal. We cannot do this alone, as education of the public is conducted through many forums.

There are multiple avenues to increase the visibility of HIV/AIDS, through public campaigns. Such forms of education could be informal through mass media, including billboard announcements, radio and television announcements, or through education and testing at community health fairs and non-health related conventions, such as a community lawn and garden show. Hutchinson, Mahlalela, and Yukich conducted a study in the Eastern Cape, South Africa to evaluate the exposure to mass media on stigma and disclosure of HIV test results (2007). Although mass media exposure did not have a direct effect on stigma, it did increase the likelihood of talking to someone about

HIV/AIDS among the female participants. Among males, there was a positive influence on HIV knowledge levels. The researchers concluded that mass media was an important way to disseminate information to increase the public's knowledge of HIV/AIDS.

Stigma was not statistically altered by the use of mass media, but it increased discussions about HIV. The more people talk about HIV, the greater the level of awareness among the public, which may help with alleviating stigma.

Although expensive to implement, serial dramatizations could be played on popular television stations, such as Music TeleVision. Serial dramatizations have been successfully used in other countries to address issues such as HIV/AIDS, women's inequality, family planning issues, and other social issues (Bandura, 2006). The serial dramas tell the stories of individuals in their everyday lives and the challenges they face. They can inform, educate, and motivate personal and social changes. O'Leary and colleagues (2007) evaluated exposure to a televised story about HIV and HIV-related stigma among 807 adolescents and adults in Botswana. Participants were divided into two groups that either watched or did not watch an episode of *The Bold and the Beautiful*, a soap opera popular in Botswana. This particular episode focused on the story of a young man who was diagnosed with HIV. HIV/AIDS stigma was measured with a five-item scale. Stigmatizing attitudes were statistically lower among the group who watched than compared to the group who did not watch the episode. The authors concluded that serial dramas that portray HIV in a non-stigmatizing and humane manner can reduce HIV related stigma. Few educational-entertainment approaches like this have been adopted in the United States. Serial dramas could center on individuals from diverse backgrounds who are living with HIV. The goals could be two-fold –

comprehensive education about living with HIV to reduce stigma and discrimination and education as awareness to further support prevention programs.

Implications for Practice

From the stories shared and themes explicated, HIV impacts every aspect of the individual's life. Although they believed their HIV was well-managed, participants did not always believe their mental health issues were addressed. Depression was a major concern of the women who participated in this study. The women have continued to have untreated depressive episodes, which may instead be related to their silencing of it, as discussed earlier. Mental health issues should be addressed in culturally appropriate ways to garner the information needed to obtain the most accurate overall understanding of the issues clients are experiencing. Education about depression and mental health issues as important and valid should be provided to clients, to help remove the stigma. Approaching the idea of therapy/counseling needs to be done in a way to make it acceptable for the client and the community.

Another important consideration within the practice setting for African American women living with HIV is disclosure. Sowell and Phillips state that although there is the risk of stigma and discrimination, thus making disclosure risky, there are many benefits of disclosure. They suggest that mental health nurses can help individuals living with HIV explore the process and consequences of disclosure through role-playing and other nursing interventions (2010). Generalist nurses also are well-educated to implement such interventions, particularly in HIV-specialty clinics, where clients are likely to feel safe. Because HIV not only affects the individual but his/her family as well, such strategies

could be implemented within the family-as-client, to support families with the complex issues of stigma and disclosure.

Coordinating visits with age, gender, and race-matched peer educators, as much as possible is another important aspect to consider. Several participants in the present study working with older non-African peer educators reported not feeling comfortable in their peer relationship. There was too great a disparity between ages, race, and gender for the women to feel comfortable sharing the intimate details of their lives. The Institute of Medicine in a recent report on the Future of Nursing suggests that we need a more diverse nursing workforce to meet the “current and future needs of the public and to provide culturally relevant care” (2011, pg. 128). In previous reports the IOM found that clients and providers had stronger relationships when there was racial and ethnic concordance. Although the IOM report specifically addressed nursing, it is not a significant jump to suggest the same would be true in the peer relationships. As peers, they may be sharing more intimate details about their lives, than with nursing staff. It may be difficult to coordinate the peer educator’s schedule to the client’s schedule. The receptionist could have a list of all peer educators with similar demographics and use a tri-monthly schedule to book client’s appointments, matching the client to the appropriate peer educator.

Many specialty clinics serving clients with complex issues, such as progressive neuromuscular disorders, have team clinics bi-monthly or monthly. Clients are seen by a comprehensive team of neurologists, physical therapists, occupational therapists, nurses, and nutritionists. A team clinic held monthly could be implemented, which would include an HIV specialist, registered nurse, Ryan White social worker, therapist, and a peer

educator matched to the client in terms of age, gender, and race. Several women in the present study were interested in working with a therapist but did not have transportation. Incorporating a therapist into a team clinic held monthly would minimize the issues of transportation to multiple appointments and would provide a safe place for women to treat depression. Family could be integrated into the team clinics, including services such as counseling/therapy, if needed, and working with nurses to gain knowledge of HIV.

Spirituality is often forgotten in the clinical setting as understandably nurses and other health care providers are attending to concerns that they may deem more important. Spirituality is important to African American women living with HIV, as it was a common theme in several studies. They also use spiritual practices as a way to cope with depression. Nurses should include spiritual beliefs and practices as part of assessments and incorporate these into plans of care. Nurses and other health care providers can partner with faith-based communities to explore creative options to address spiritual health of African American women living with HIV and to reduce stigma in faith-based communities through educational initiatives.

In a recent community-based participatory research, faith-based organizations partnered with an HIV clinic to develop and implement a program, Your Blessed Health, that addressed HIV/AIDS, sexually transmitted infections, and risk behaviors among African American adolescents and young adults (Griffith et al., 2010). They expanded the program to include 42 faith-based organizations. Several faith-based organizations partnered with the Jacques Initiative, a comprehensive clinic that provides services to individuals with HIV to increase HIV testing in Baltimore. Through their collaboration with Project Shalom, more than 4,000 individuals have been tested. A unique aspect of

this program is that faith-based community members volunteer to conduct the testing. Programs such as these engage faith based communities in the health of African Americans, increase knowledge about HIV which could help to reduce HIV-related stigma.

Implications for Policy

HIV-related stigma, as discussed previously is a significant issue for all individuals living with HIV. There should be financial support for mass media campaigns through the collaboration of private and public sectors. Kaiser Family Foundation has recently partnered with 60 African American celebrities to increase the visibility of HIV among the African American community (2012). To coincide with National Black HIV/AIDS Awareness Day on February 7, new public service ads, featuring popular African American television and film actors and other celebrities, were debuted through Greater than AIDS, collaboration among public and private sectors. The goals of Greater than AIDS are to increase knowledge and decrease stigma. Although the news report detailed this new program, it did not address if there would be formal measures of HIV knowledge and stigma as a result of viewing the ads. Few studies have tested national level interventions, such as mass media, to reduce stigma (Brown, Macintyre, & Trujillo, 2003). So not only should we consider creative forms of mass media education, we need to evaluate these programs for efficacy and efficiency.

Although no data were collected on health insurance, more than half of the women were not working, so may have had Medicaid or were enrolled in the Ryan White Treatment Extension Act. This legislation, enacted in 1990, is for individuals living with HIV/AIDS who do not have health insurance or are underinsured to acquire

comprehensive services to manage their disease. The act is complex with multiple components to address different needs. Part D provides services for women, infants, children, youth and their families. Although these services are quite comprehensive including primary care, transportation to medical appointments, outreach to recruit and retain clients, the services do not include counseling. There is a prevalence of depression among African American women living with HIV that is generally related to the diagnosis. Many are living in lower socioeconomic situations and cannot afford to pay for a therapist. Expanding services to include therapy with a master's prepared social worker or psychiatric Advanced Practice Registered Nurses could be beneficial to this population to alleviate psychological distress. Another option would be to require Ryan White case managers to have adequate training in counseling/therapy, so they could provide such services during primary care visits.

Implications for Research

There are several implications for further research as a result of the present study. First, it may be important to conduct qualitative research exploring the lived experiences of young African American women living with HIV who are not engaged in medical care to explore reasons they are not engaged in care, barriers to care, and how they are managing their disease. Despite the multiple complexities which the women in the present study were facing, they were actively engaged in comprehensive health management of their disease. There may be additional and even more complex issues for women living on the margins of medical management that need to be evaluated.

Many women have untreated depression and few resources for addressing and treating it. Confounding the barriers to treatment is the expressed desire to protect

themselves from the public. One-on-one nursing interventions provided in the privacy of the women's home and grounded in psychotherapy concepts to improve depression and coping skills warrant investigation. Several studies have evaluated telephone-delivered psychotherapy within different populations, including rural HIV-positive individuals with depression (Ransom, Heckman, Anderson, Garske, Holroyd, & Basta, 2008) and middle and older adults living with HIV (Heckman, Barcikowski, Ogles, et al, 2006). There are mixed results from these studies. Telephone therapy was effective in reducing depressive symptoms among rural HIV-individuals. In the study of middle-aged and older adults, participants reported improved coping strategies, although there was no statistically significant decline in depressive symptoms following the 12 session intervention. Nurse researchers have used telephone interventions with other populations with success. Teel and Leenerts (2005) conducted a pilot study to evaluate a Self-Care telephone intervention with caregivers of individuals with dementia. Caregivers reported that they learned helpful information at each session that they planned to use as they engaged in self-care. Telephone interventions were used in three studies because clients lived in rural settings. Although the women who participated in this study live in an urban setting, they too had access issues whether it was transportation or concern about being in public.

Community based participatory research (CBPR) provides an active voice to the study participants; as such it gives a voice to individuals who have been marginalized in society. CBPR with African Americans living with HIV would allow the women to create nursing interventions that are culturally congruent and that have meaning to them. Through CBPR, the co-researchers could explore ways to decrease aloneness and

isolation that were pervasive in the present study. CBPR has been used to increase HIV/AIDS awareness in faith based communities. CBPR, with partnerships between the health care community and faith-based communities would be an excellent way to increase resources for African American women living with HIV. Further ideas for the partnership include exploring ideas to increase spiritual support for women living with HIV that comes from the faith-based community, to decrease their feelings of isolation.

Last, there are significant issues of HIV-related stigma that marginalize individuals living with HIV to the outskirts of society. CBPR with faith-based communities also is necessary to address HIV-related stigma that continues to invade these communities. Although there have been many national campaigns to increase education, the impact on individual's knowledge or perceived stigma has not been evaluated. Such campaigns are costly and if they do not have a significant impact, we need to evaluate other methods of providing education.

Conclusions

This research study provided a brief snapshot into the lives of eleven African American women living with HIV. The overarching pattern portrays the living with HIV, which has impacted every aspect of their lives. The themes explicated provide support for the pattern and describe the complexities of the participants' lives. Physically, the women were able to participate most of the time in their everyday normal routine. They did, however, experience effects from the disease or medications that forced them to alter routines. Emotionally and mentally, the women were experiencing significant psychological distress. Family relationships were destroyed, friendships severed, and hostility and contempt felt within the community. Shielding themselves

was a form of protection, which unfortunately resulted in isolation. The themes that were explicated from the study inform education, nursing practice, health care policy, health care research.

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Appendix A: Informational Flier


University of Kansas
Medical Center School of
Nursing

The Experiences of Living with HIV Disease

We invite you to participate in a study if you are an African American Female living with HIV disease & are between the ages of 18 and 35.

You will receive a \$40 gift card for your time for each of 2 visits

You will be interviewed two times and asked questions about how you take care of yourself and if spirituality is important in your self-care practices.

All information you provide is confidential.

If you are interested in participating in this study :

Please contact:

Jill Peltzer at 913-588-3396 or 816-808-6843 or by
email: jpeltzer2@kumc.edu

Appendix B: Letter of Support from KC Free Health Clinic



3515 Broadway
Kansas City, MO
64111-2537
(816) 753-5144
Fax (816) 753-0804
www.kcfree.org

May 10, 2010

Jill Peltzer, RN, MS
University of Kansas School of Nursing
3901 Rainbow Boulevard
Kansas City, Kansas 66160

We have reviewed your proposal to conduct the study "**Exploring the Lived Experience of Young African American HIV Infected Women**".

The Ryan White Treatment Modernization Act, Part D educates clients about research and research opportunities and informs all clients about the benefits of participation and how to enroll in research. *The Family Project of the Kansas City Free Health Clinic* (primarily funded by Ryan White Part D), supports efforts for the discipline of nursing to better understand the lives of young African American women living with HIV infection in order to develop comprehensive and culturally appropriate nursing interventions that support their health.

To support participation, our program will do the following:

- Continue to provide general education about benefits of participation research and research opportunities
- Make information about the, "**Exploring the Lived Experience of Young African American HIV Infected Women**" study available to clients (i.e. sharing marketing material, and disseminating your informational letter about your study to interested clients)
- Encourage funded Family Centered HIV Case Managers in the process of identifying their clients who meet the inclusion criteria for referral
- Share results/findings of your study with staff, peer educators, consumer advisors and clients of *The Family Project*.

Please feel free to contact us should you need additional assistance.


Heather Brungardt, LCSW, LMSW
Director of Community Services


Amber Rossman, LMSW
Manger of HIV Case Management (and The Family Project Coordinator)



Established 1971

Appendix C: Letter of Support from Ryan White Case Management



Health Department

2400 Troost Avenue, Suite 1000
Kansas City, Missouri 64108

(816) 513-6230
Fax: (816) 513-6292

May 7, 2010

Jill Peltzer, RN, MS
University of Kansas School of Nursing
3901 Rainbow Boulevard
Kansas City, Kansas 66160

Dear Jill:

I have reviewed your proposal to conduct the study "Exploring the Lived Experience of Young African American HIV Infected Women". I support your efforts for the discipline of nursing to better understand the lives of young African American women living with HIV infection in order to develop comprehensive and culturally appropriate nursing interventions that support their health. I approve of the Ryan White Case Managers identifying their clients who meet the inclusion criteria and disseminating your informational letter about your study to these clients.

Please feel free to contact me should you need additional assistance.

A handwritten signature in black ink that reads "Rosalyn Madden". The signature is fluid and cursive, with the first name "Rosalyn" and last name "Madden" clearly distinguishable.

Rosalyn Madden, MSW, LCSW
Social Service Supervisor
2400 Troost Avenue, Suite 1000
Kansas City, MO 64108
Telephone: (816)513-6214
Fax: (816)513-6292

Appendix D: Letter of Support from Truman Medical Center Infectious Disease Clinic



Hospital Hill
2301 Holmes
Kansas City,
Missouri 64108

816.556.3000

November 22, 2010

Jill Peltzer, RN, MS
University of Kansas School of Nursing
3901 Rainbow Boulevard
Kansas City, Kansas 66160

Dear Ms. Peltzer:

I have reviewed your proposal to conduct the study "Exploring the Lived Experience of Young African American HIV Infected Women". I support your efforts for the discipline of nursing to better understand the lives of young African American women living with HIV infection in order to develop comprehensive and culturally appropriate nursing interventions that support their health. I approve of your being available in the ID clinic to clients who would like to find out more about your study.

Please feel free to contact me should you need additional assistance.

A handwritten signature in cursive script that reads 'Dawn Sutton'.

Dawn Sutton, RN
Ambulatory Director

**Appendix E: Letter of Support from University of Kansas Physicians Infectious
Disease Clinic**

The University of Kansas Medical Center

School of Medicine
Department of Internal Medicine
Division of Infectious Diseases

Daniel R. Hinthorn, M.D., FACP
Chien Liu, M.D. MACP, Emeritus
Michael Luchi, M.D.
Stephen Waller, M.D.
Lisa Clough, M.D.
Albert Eid, M.D.
Fernando Merino, M.D.
Wissam El Atrouni, M.D.
Kassem Hammoud, M.D.
Nivedita Ganguly, M.D.
Dana Hawkinson, M.D.

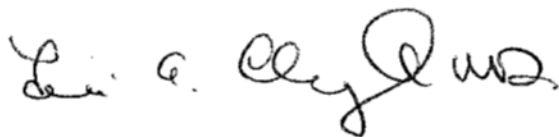
December 3, 2010

Jill Peltzer, RN, MS
University of Kansas School of Nursing
3901 Rainbow Boulevard
Kansas City, Kansas 66160

Dear Jill:

Thank you for meeting with me to review your proposal to conduct the study "Exploring the Lived Experience of Young African American HIV Infected Women". I support your efforts to better understand the lives of young African American women living with HIV infection in order to develop comprehensive and culturally appropriate nursing interventions. I approve of the Infectious Diseases clinic staff at the University of Kansas Medical Center identifying their patients who meet the inclusion criteria and disseminating your informational letter about the study to those patients.

Please feel free to contact me if additional questions arise.



Lisa A Clough MD
Assistant Professor of Medicine
Division of Infectious Diseases

Appendix F: Institutional Review Board Approval Letter

The University of Kansas Medical Center

Human Research Protection Program

July 20, 2010

Project Number: 12254
Project Title: Exploring the Lived Experience of Young African American HIV Infected Women
Sponsor: Academy of Medical Surgical Nurses
Protocol Number: N/A
Primary Investigator: Leonie Pallikkathayil, Ph.D.
Department: Administration - School of Nursing
Meeting Date: 06/08/2010
HSC Approval Date: 07/19/2010
HSC Expiration Date: 07/18/2011
Type of Approval: Expedited f (7)

Dear Investigator:

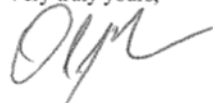
This is to certify that your research proposal involving human subject participants has been reviewed and approved by the KUMC Human Subjects Committee (HSC). This approval is based upon the assurance that you will protect the rights and welfare of the research participants, employ approved methods of securing informed consent from these individuals, and not involve undue risk to the human subjects in light of potential benefits that can be derived from participation.

Approval of this research is contingent upon your agreement to:

- (1) Adhere to all KUMC Policies and Procedures Relating to Human Subjects, as written in accordance with the Code of Federal Regulations (45 CFR 46).
- (2) Maintain copies of all pertinent information related to the research study including, but not limited to, video and audio tapes, instruments, copies of written informed consent agreements, and any other supportive documents in accordance with the KUMC Research Records Retention Policy.
- (3) Report unanticipated problems to the HSC by completing the Internal or External HSC Unanticipated Problem/Adverse Event reporting form, as applicable.
- (4) Submit deviations from previously approved research activities which were necessary to eliminate apparent and immediate dangers to the subjects by using the KUMC Protocol Deviation Report.
- (5) Submit Amendments to the HSC for any proposed changes from the previously approved project using the Request for Amendment form. Changes may not be initiated without prior HSC review and approval, unless a delay in implementation would place subjects at risk.
- (6) Submit Continuing Review Form (CR Form) to the KUMC HSC before the expiration date. Federal regulations and HSC policies require continuing review of research at intervals appropriate to the degree of risk, but not less than once per year.

If you have any questions regarding the human subject protection process, please do not hesitate to contact our office.

Very truly yours,



Daniel J. Voss, M.S., J.D.
 IRB Administrator

Appendix G: Informed Consent Form

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Exploring the Lived Experience of Young African American HIV Infected Women

RESEARCH CONSENT FORM

**Exploring the Lived Experience of Young African American HIV Infected Women
Protocol #**

INTRODUCTION

You are being asked to join a research study learning about the experiences of being a young African American woman living with HIV disease. You are being asked to take part in this study because you are an African American woman and you have HIV disease. You do not have to be a part of this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at the clinic at which you regularly receive care.

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research.

You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place in the community of Kansas City, through the University of Kansas Medical Center (KUMC) with Leonie Pallikkathayil, PhD, RN, as the primary investigator and Jill Peltzer, RN, MS as the co-investigator. About 15 women will be in the study.

BACKGROUND

HIV disease has continued to increase among women living in the United States. In particular, African American women have been affected more than Caucasian and Latina women. Despite the successes in HIV treatment, HIV disease has been one of the leading causes of death for young African American females, between the ages of 18 and 35 years. There are only a few studies that have examined the lives of young African American women living with HIV disease, and there are even fewer studies that have explored how young African American women take care of themselves, and how they use spirituality and religious practices in their self-care practices.

PURPOSE

By doing this study, researchers hope to learn how young African American women live with HIV disease, and in particular, the influence of spirituality in their lives. Additionally, researchers hope to find out how young African American women with HIV

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disease use self-care practices, such as taking medications, to manage their disease.

PROCEDURES

If you are eligible and decide to participate in this study, your participation will last approximately two to three months. Your participation will involve participating in two in-person interviews by one of the researchers in the setting of your choice, such as your home, a private room at a library, or a private room at a community center. The interviews will be about your daily life while living with HIV infection, such as what gives you hope, how do you take care of yourself, what are your spiritual practices. We will also ask you questions such as if you have children, how long you have had HIV disease, what type of medical treatment you are receiving. Each interview will last approximately 45 to 90 minutes and will be audio-taped. The audio-tapes will be destroyed upon completion of the study. The interviews will occur within a span of two to three months. For example, if your first interview is in July, your second interview would be in August or September.

RISKS

There are minimal risks or discomforts to participating in this study. Talking about living with HIV disease may be stressful. You may feel uncomfortable by some of the questions that the researcher asks you. You do not have to answer any questions. If the questions cause you to be sad or anxious, the interview can be stopped. If you would like to speak to a professional, a referral will be made to an appropriate health care professional at the clinic or organization at which you receive services. There may be other risks of the study that are not yet known.

NEW FINDINGS STATEMENT

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

BENEFITS

You will not directly benefit from this study from participating in this research study. Researchers hope that the information from this research study may be useful in the development of nursing interventions that incorporate spirituality into self-care practices to help young African American women with HIV disease manage their disease.

ALTERNATIVES

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at the clinics at which you receive services, nor will it have an effect on any current or future services through KU Medical Center.

COSTS

There is no cost for being in the study.

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Exploring the Lived Experience of Young African American HIV Infected Women

PAYMENT TO SUBJECTS

You will be given a 20 dollar gift card to a local grocery store for each in-person interview that you participate in. After completion of each of the interviews, you will be given the gift card. If you participate in both interviews, you will receive 2 twenty dollar gift cards during the research study. If you decide to withdraw before the end of the study, you will be paid for the interview that you have completed.

IN THE EVENT OF INJURY

If you have a study related problem during this study, you should immediately contact Jill Peltzer at 913-588-3396.

INSTITUTIONAL DISCLAIMER STATEMENT

If you think you have been harmed as a result of participating in research at the University of Kansas Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Under certain conditions, Kansas state law or the Kansas Tort Claims Act may allow for payment to persons who are injured in research at KUMC.

CONFIDENTIALITY AND PRIVACY AUTHORIZATION

The researchers will protect your information, as required by law. Absolute confidentiality cannot be guaranteed because persons outside the study team may need to look at your study records. The researchers may publish the results of the study. If they do, they will only discuss the themes that are common to the participants. They may include quotes from your interviews in the findings, however, your name will not be used; instead a fake name will be used in any publication or presentation about the study.

Your health information is protected by a federal privacy law called HIPAA. By signing this consent form, you are giving permission for KUMC to use and share your health information. If you decide not to sign the form, you cannot be in the study.

The researchers will only use and share information that is needed for the study. To do the study, they will collect health information from the study activities. You may be identified by information such as name, address, phone, date of birth, or other identifiers. Your health information will be used at KU Medical Center by Dr. Pallikkathayil and Ms. Peltzer, members of the research team, the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies. Study records might be reviewed by government officials who oversee research, if a regulatory review takes place.

All study information that is sent outside KU Medical Center will have your name and other identifying characteristics removed, so that your identity will not be known. Because identifiers will be removed, your health information will not be re-disclosed by

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Exploring the Lived Experience of Young African American HIV Infected Women

outside persons or groups and will not lose its federal privacy protection.

Your permission to use and share your health information remains in effect until the study is complete and the results are analyzed. After that time, researchers will remove personal information from study records.

QUESTIONS

Before you sign this form, Jill Peltzer, or other members of the study team should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects Committee at (913) 588-1240. You may also write the Human Subjects Committee at Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at the organizations at which you receive services. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

You have the right to cancel your permission for researchers to use your health information. If you want to cancel your permission, please write to Dr. Pallikkathayil. The mailing address is Dr. Pallikkathayil, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160. If you cancel permission to use your health information, you will be withdrawn from the study. The research team will stop collecting any additional information about you. The research team may use and share information that was gathered before they received your cancellation.

CONSENT

Jill Peltzer has given you information about this research study. She has explained what will be done and how long it will take. She explained any inconvenience, discomfort or risks that may be experienced during this study.

By signing this form, you say that you freely and voluntarily consent to participate in this research study. You have read the information and had your questions answered. You are giving me permission to contact you through your case manager.

You will be given a signed copy of the consent form to keep for your records.

Print Participant's Name

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Exploring the Lived Experience of Young African American HIV Infected Women

Signature of Participant

Time

Date

Print Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

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Assurance #: FWA00003411

Appendix H: Demographic Data

Name: _____ Pseudonym: _____

Telephone Number: _____ (For scheduling interviews)

Alternate Numbers: _____ (For scheduling interviews)

Best time to call: _____

Age: _____

Educational Level: _____

Children: _____

Children living in the household: _____

Years living with HIV: _____

Stage of Disease (CD4 count; viral load): _____

Medication Adherence: _____

Spirituality prior to diagnosis of HIV: _____

Date of 1st Interview: _____

Gift card provided (date provided and type of card): _____

Date of 2nd Interview: _____

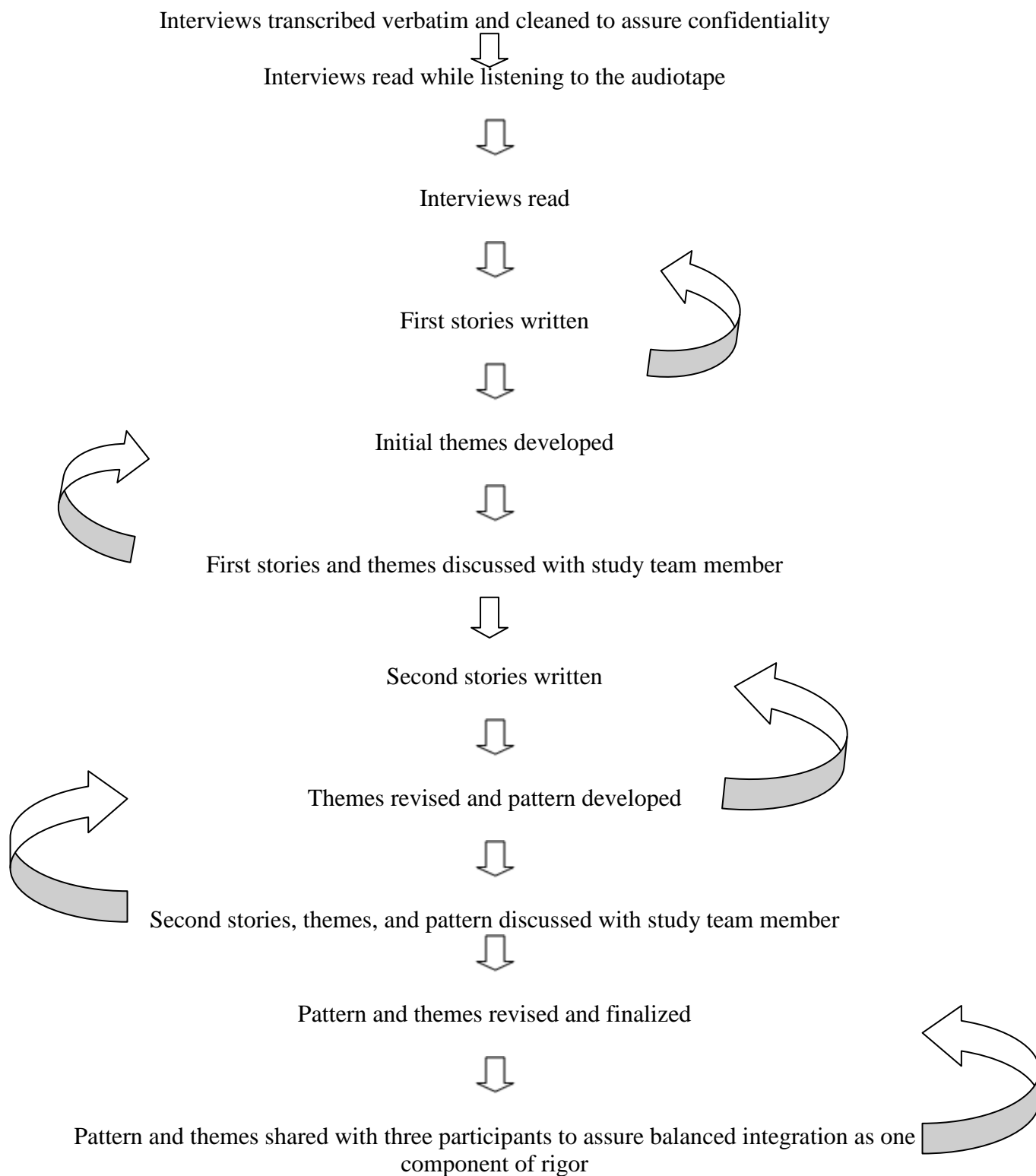
Gift card provided (date provided and type of card): _____

Appendix I: Referral List

(816) 931-0030 – National Association of Mental Illness (NAMI – based in KC)

ACTION	Situation	Contacts
Refer to helping professional	<ul style="list-style-type: none"> - Requests assistance with general psychosocial issues or barriers to care. - Identifies passive anxiety about situational issues, depressive symptoms, unresolved mental health concerns - Relays thoughts of hopelessness (without plan or recent attempts to harm self and is willing to self access services) 	<p><i>In addition to professional/departmental protocol:</i></p> <ul style="list-style-type: none"> - Ask about helping professionals already working with the client (nurse, social worker, case manager). - Seek commitment to contact this helping person within 5-7 days to address concern. - Offer Mental Health Crisis Line: <p>1-888-279-8188 1-800-SUICIDE</p>
Make Referral Call professional associated with client referral	<ul style="list-style-type: none"> - Relays thoughts of harming self or others (without plan or recent attempts to harm self and commits to seeking help) - Displays actions or verbalizations that are not appropriate for environment 	<p><i>In addition to professional/departmental protocol:</i></p> <p>Mental Health Crisis Line: 1-888-279-8188 Suicide Hotline: 1-800-SUICIDE Truman Medical Center Mental Health Crisis Response: 816-404-5700 Domestic Violence 816-545-4700 Follow up contact with professional associated with referral (i.e. Case Manager or CM Supervisor)</p>
Call 911	<ul style="list-style-type: none"> - Expresses intent or recent attempts to harm self or others - Is not oriented to person, place or time - Displays actions or verbalizations that are not appropriate for environment AND displays potential for harming self or others 	<p>Dial 911, request C.I.T. Responder</p> <ul style="list-style-type: none"> - Crisis Intervention Trained responders specialize in sensitivity toward those dealing with mental health/illness crisis. <p><i>After addressing crisis and safety of self and client, follow professional/departmental protocol.</i></p>

Appendix J: Data Analysis Process



Appendix K: Second Stories

Alisa's Story

When I first met Alisa, a young woman in her mid-thirties, she seemed to be the epitome of strength, standing tall with a firm handshake and eager to share her story. Alisa is married with five children. Diagnosed nine years ago, Alisa has been juggling living with a chronic, fatal disease, with being a wife and mother. It is not only Alisa who has to cope with the chronicity of HIV disease. Providing support to Alisa, her husband and children also have to cope with their mother's life that is defined by CD4 counts and viral loads. Should these counts shift, the balance between life and death becomes more acute, affecting everyone in her family. Living with HIV is not something that only Alisa has to do; her family also lives in the everydayness of HIV disease. Despite her high CD4 counts, Alisa remains on medication therapy, as a way to prolong her life.

Alisa's life changed forever when pregnant with her fourth child, she found out she was HIV positive. Despite using protection, she was betrayed by her partner, as she was informed by his family that he had AIDS. In her new marriage, Alisa's initial reaction was to tell her partner to walk away from her. Not feeling worthy of love, she tried to protect her husband and possibly create a new life without him. Her husband has stayed in the relationship, reinforcing for Alisa that there are still some men with integrity in the world. Facing a life now filled with medications, blood tests, doctor's appointments, she was angry, frustrated, questioning why her? At the time of diagnosis, Alisa was emotionally overwhelmed and was not ready to understand the implications of being HIV infected.

Through not always spiritual, Alisa now draws upon a strong belief in God for strength.

Unfortunately, she no longer believes that she can attend church services. Told by the pastor and his wife that she would have to reveal her HIV status to the congregation if she wanted to continue to attend services, she has instead chosen to uphold her spiritual and religious beliefs privately. This has created a void in Alisa's spiritual world, as she desires a religious community. This experience also reinforced that to protect herself, she has to keep her disease hidden. However, Alisa seems ready to talk about living with HIV. Concerned about the reaction by her fellow classmates, yet wanting to provide education, she shared her story about her life with HIV disease. Instead of being humiliated, discriminated against, Alisa found herself surrounded by young individuals who supported her and wanted to know more about a disease that has significantly impacted her and her family.

Alisa's life living with HIV is not easy. A fragility emerges as she continues to tell her story. She suffers from severe mood swings, resulting from knowing that she has an incurable disease. Seeking counseling and taking anti-depressants helps her cope with her depression; but ultimately she is alone, living with HIV disease. Caring for herself and caring for her family result in a conundrum of who needs to be cared for first: is it her, or her family? It seems that by caring for herself first, she is then caring for her family, but Alisa may not necessarily have that belief.

Alisa is quite vocal about preparing for her death, ensuring her children are taken care of. This is a real concern, as her children are all from different partners. She questions, not only her children's well-being, as she faces the future, asking not if she will die, but when it will happen. She is trying to make sure that her children are well prepared to face their future without her. But is she also ensuring her own legacy?

Diana's Story

Diana preferred to meet both times away from her home. Accompanied by her sister and cousin the first time, she understandably wanted to create a safe place to share her story. Diana was diagnosed as a teenager. Although she had a premonition that she was HIV positive, she was devastated when she got the positive test results. Without a deep belief in God and the birth of her first nephew, she would have committed suicide. Her nephew gave her a reason to live. Embarrassed and ashamed, Diana did not initially tell her mother or siblings. Once the high school staff found out Diana's HIV status, they contacted her mother. Now a support for Diana, her mother was initially disappointed in her.

Diana has experienced multiple layers of betrayal. Her father sexually abused her when she was a toddler. She has experienced betrayal by family members, outside of her immediate family, health care professionals and education staff. Diana has family who do not interact with her once they found out her diagnosis. She was asked to find a different school once the staff found out her diagnosis. She is nervous about seeing new healthcare practitioners, since she was negatively judged for being HIV and pregnant at an OB clinic and asked to seek services elsewhere. The individuals who should have provided a safe space have instead created a shameful, uncomfortable environment for Diana.

Diana tries to shield herself from additional betrayal by telling few individuals her HIV diagnosis. She has to have complete trust in her friends before she will tell them. Diana has not participated in many support groups, again believing that she needs to be very private about having HIV disease. She feels that she is alone with her diagnosis.

Diana continues to have pervasive depression. She does see a counselor, but prefers to not be on medication. Drawing on her spirituality, she talks to God every night as a way to assist with the depression. She is comfortable with the congregation at her church, but they do not know her disease status. She is not interested in continuing medication therapy after the pregnancy, despite understanding that without it, her counts will eventually drop and she could have a serious illness or die. In fact, Diana often feels like she is dying. Maybe the desire to stop medication is because she feels like it is futile. For Diana, the future is unclear. Her baby gives her hope for the future, however, the future is still very different from what she had envisioned. Until there is a cure, Diana does not seem to be able to come to terms with having HIV disease.

Dion's Story

Dion is a young new mother living with her significant other. Both Dion and her boyfriend were recently diagnosed with HIV infection. Because she had a negative test prior to this relationship, Dion was hurt and shocked when, as part of her prenatal care, her HIV test was positive. Although feeling betrayed by her boyfriend and also believing that he was betrayed, her greatest concern was her baby's health. She alludes to her own feelings of guilt, suggesting that she should have been more careful. She does not try to dwell on negative feelings, instead is pragmatic and focusing on optimizing her health. Due to her careful attention to her medication regimen, exercise, and a healthy diet, her daughter is HIV-negative and Dion's counts are good. Dion and her boyfriend support each other, with reminders to take their medications and keeping one another accountable for themselves and their daughter.

Dion made the difficult decision to tell her parents and siblings her diagnosis. Because

her father was with her at the time of the diagnosis, she felt like she had support when she learned her status. Dion's relationship with her parents has become stronger in the face of HIV. However, given one of her brother's reaction to her diagnosis, she has not disclosed to her other siblings. Feeling betrayed by her brother, she wants to avoid further betrayal. Unsure of their reactions, Dion protects herself and her boyfriend by withholding their HIV status from other family members. Dion is very protective of her nuclear family, shielding them from any possible betrayal, by keeping her HIV status very private. Although she did not articulate this, Dion and her boyfriend have created a safe space to live with HIV infection.

Spirituality and religion do not play an important part of her life. Although she occasionally attends church, she does not uphold a strong belief in God and does not draw upon spirituality for support. Her new daughter provides hope for her future; Dion looks to her daughter's life for relief from the depression that surrounds her since her diagnosis of HIV disease. Instead of seeking treatment for her depression, Dion relies on interactions with her immediate family. Dion is reluctant to seek professional help. Overall, there seems to be a disconnect to what Dion is really feeling about living with HIV disease and what she reveals.

Dutchess' Story

Dutchess, a young woman in her mid-twenties, greeted me at her small home with an engaging smile and a story to tell. At first, she seemed to be very strong and coping well with a new diagnosis of HIV infection. However Dutchess was internally very fragile, revealing at our second meeting that she had been putting up a front for everyone, not letting anyone know how distressed she was upon learning her new diagnosis. Applying

for life insurance, Dutchess was tested for HIV as part of the work-up. Having recently had a negative test, she was shocked and devastated when she was denied coverage and contacted by the Health Department that her test was HIV-positive. Initially overwhelmed by learning about CD4 counts and viral loads, Dutchess quickly became involved in support groups and HIV classes to be educated and informed. She is now prepared to be a peer educator and eager to help other HIV-positive individuals.

Betrayed by the person who knowingly transmitted the virus to her, Dutchess initially was very angry, but has tried to work through it. She also takes responsibility for what happened, sharing that the man has to deal with his part, and she has to figure out her side of the story. Unfortunately, Dutchess has had multiple episodes of betrayal from family and health care providers. While Dutchess was hospitalized with a serious infection, her aunt posted Dutchess' photo and HIV status on a social media website. Subsequently, in a community that was once safe for her, she was now experiencing stigma. Dutchess has faced stigma from nurses at a local hospital. Not realizing she could hear their conversation, they spoke disparagingly about HIV-positive individuals. Dutchess is very careful with whom she shares her HIV status, sharing that she feels that the public sees HIV-positive individuals as lepers with a very contagious illness.

After being the focus of testimonials about sinning during church service, Dutchess now prefers to worship privately. Betrayed by the congregation and again by her family, Dutchess believes that there is hypocrisy in organized religion. She still has a deep faith in God and a clearer picture of where she wants to be spiritually since her diagnosis. Writing fictional stories about her life, Dutchess creates a safe place to work through her thoughts and feelings. Despite the stigma from some family members, Dutchess'

immediate family, including her significant other, son, and mother are very supportive. Her son is her advocate, making sure she takes care of herself. Despite their support, they do not always understand what Dutchess is experiencing. She is ultimately alone while living with HIV and had depression as a result of the disease.

Dutchess' son gives her hope for the future; without him she may have given up on living with HIV infection. However there is anguish she may not always be here for him and his significant life events. Her future is different now. Dutchess has plans for her future as a result of her diagnosis. She would like to eventually become a behavioral specialist and work with HIV-positive individuals.

Jacqueline's Story

Jacqueline is a young woman clearly in search of meaning in her life. Feeling abandoned and betrayed by her sister, a person who clearly is very important in her life, she is trying to plan a new future, away from the Midwest. She feels like she is the only person in her town that is HIV-positive. There are few support groups and women's retreats for her to connect with other HIV-positive women. She is alone and very isolated living with HIV. Diagnosed at birth, Jacqueline did not find out that she was HIV-positive until she was a teenager. Her mother died from AIDS while she was a toddler. Her aunt, who raised her, did not share her diagnosis with Jacqueline. It was not until Jacqueline and her sister moved to the Midwest that she began medication therapy and routinely saw a healthcare practitioner. In denial that she had a serious illness, Jacqueline quit taking her medication and ended up in a coma for several weeks. This episode forced her to "wake up" and she began to take better care of herself, adhering to her medication regimen and seeing a practitioner regularly.

She has recently stopped taking her medications and does not seem to care about the possible consequences. She is depressed and is not seeking treatment. She recently considered giving her young son up for adoption and was feeling suicidal. Her son provides hope for the future, but it does not seem to be enough. Jacqueline does not have strong spiritual beliefs from which to draw upon for strength.

Jacqueline believes there is significant risk with disclosure of her HIV status. She suspects people have become more distant when they learned her diagnosis. She has also felt humiliated in a gathering of individuals she thought were friends, when several who thought her son was also HIV-positive would not let their children play with him. Jacqueline protects herself by not telling anyone, unless she may become sexually involved. Whether real or perceived, abandonment and betrayal have been significant in her young life.

With little hope for the future and no clear plans, it seems that Jacqueline does not have a lot of control over her life. Besides her son, the only optimism she displayed was when talking about writing a book about her life.

Katelyn's Story

Katelyn, a sensitive, thoughtful young woman seems very vulnerable, sad, and fragile. Diagnosed four years ago while receiving prenatal care, she went into an intense depression. Feeling very exposed in public, she stayed at home as a way to protect herself. Katelyn has not been able to reconcile living with HIV infection. She has tremendous guilt and self-hatred about her HIV status. Katelyn has to force herself to not see an HIV-positive individual when she looks in the mirror every morning. She remains depressed, feeling that she has let a lot of people down, including herself. She

does not live a normal life anymore, always trying to be cautious to protect herself and her family. Small, insignificant everyday events are now constant reminders that she is different from everyone else.

Katelyn was initially very angry at God and would not pray or attend church services. Spirituality and her faith in God are now very important to help her cope with living with HIV infection. She is trying to reach a place where she is spiritually comfortable with her diagnosis, stating that this may be a blessing in disguise and that she is meant to help others. Although trained as a peer educator, she is not ready to work with other HIV-positive individuals. There is still a risk with disclosure, possibly concerned about betrayal. Katelyn has experienced betrayal within her family as a result of her HIV status. Her father and brother, both seemingly unable to accept Katelyn's diagnosis have distanced themselves. Once a part of a family, Katelyn now feels separated by HIV. She was also betrayed by the NICU team when her daughter was born. Protecting herself, she avoids further opportunities for betrayal and stigma by keeping her diagnosis private. Katelyn seems to cognitively understand that she may live a full, long life, but emotionally and mentally has not reached that same understanding. She has little hope for the future, stating that she used to want to become a nurse or CNA, but does not see how that would be possible now. She even indicated that her life would be shorter and became tearful, sharing her anguish about the possibility of leaving her daughter, the one person who gives her hope and for whom she lives.

Lizbeth's Story

Lizbeth, a new mother, was diagnosed with HIV as an adolescent. She was shocked when her boyfriend told her he was HIV-positive and devastated when she received the

news that she was also HIV-positive. Although betrayed by him, she has resolved her feelings of anger and has remained in a relationship with him. Being in high school and newly diagnosed was extremely difficult for Lizbeth. She was alone and depressed, isolating herself from her friends and acquaintances, afraid of what they would say if they knew her diagnosis. Today, she continues to express fear of being shunned; thus she has kept her diagnosis to herself; only her boyfriend and his immediate family know. Lizbeth has no immediate plans to tell her family, concerned that they will not maintain confidentiality.

Lizbeth would like more support, but protecting herself and subsequently feeling isolated is safer for her. Although she can talk to her boyfriend, she feels a void of relating to women and expressed that she often feels alone. Lizbeth would like to go to counseling, but has not done anything to achieve that goal and is not forthcoming about her desire to work with a counselor. There are contradictory beliefs about her life; it is life-changing, frustrating, and challenging, but she is used to it and it is common now. It seems that she lacks insight about her disease and it may create a barrier to living an authentic life.

Lizbeth is a spiritual woman and attend church and bible study regularly. She draws upon her spirituality through prayer and reading the bible as a way to stay strong and positive. Since having her daughter, she has had some challenges fully caring for herself, such as missing her medications more often. She puts her baby first and sometimes she neglects herself. When facing the future, Lizbeth finds hope and strength in her daughter and boyfriend. She used to dream of being a nurse, but thinks her HIV status will prohibit that. Although outwardly strong, Lizbeth seems very young and fragile.

Mikayla's Story

Mikayla, a woman in her twenties, has experienced significant trauma in her young life. Diagnosed four years ago during routine prenatal care, Mikayla became very depressed and suicidal. Although devastated, she had had a premonition about the diagnosis. She had a dream that she was HIV-positive the night before her appointment. Due to her lack of education, she did not know she could have a healthy baby and that she could live a long life with appropriate treatment. Thus, she saw suicide as her only option. Her boyfriend convinced her to not act on her thoughts, reminding her that needed to live for the baby.

Mikayla is very angry at the individual who transmitted to her. She has not been able to resolve that anger. Feeling betrayed by him, she now holds a lot of anger toward men in general. She also seems to have unresolved anger towards herself, sharing that she feels disgusted for having HIV. She has not reconciled her feelings about living with HIV, seemingly trying to remain in denial. HIV is just one more negative experience in her life.

Mikayla describes a life of betrayal and abandonment from her mother and siblings. She was put into DFS as an adolescent, while her siblings remained with her mother. Her relationships with her family are tumultuous and often violent. Not only do they not provide support, her sister is raising Mikayla's oldest child. The child who was supposed to love her unconditionally instead calls her sister mom and is giving her sister that unconditional love.

Mikayla has nothing that provides hope for her future. Angry at God for letting her children be taken away and for allowing her to become HIV-positive, she does not turn to

spirituality for hope and strength. The one person who seems to bring joy to Mikayla's life is her boyfriend. He makes her feel like a queen, an experience that she seems Mikayla has not had the opportunity to experience previously. However, he is incarcerated, so she feels even more isolated. Although the walls in her small apartment often feel constraining, it is the only place where she really feels safe.

Natalie's Story

Natalie, a young female in her early 20s, has been alone most of her life, despite growing up in a large family. Neglected by her parents as an infant, Natalie was stuck with a used drug needle which resulted in her acquiring HIV. Natalie's father died from AIDS when Natalie was young. Since her mother continued to use IV drugs, an aunt adopted Natalie and her siblings and brought them to the Midwest, where they were raised. Natalie grew up very lonely, not being allowed to play with other children or attend activities with her siblings. Unaware of her diagnosis, she did not understand that her Aunt was trying to protect her. It was not until she was a teenager that Natalie found out she was HIV-positive. Feeling betrayed by her aunt for withholding this information, she hated everyone, particularly her parents. The very individuals who were supposed to protect her from harm instead changed her life forever.

Natalie does not feel normal and has unrelenting depression. It can be so severe, she questions if she wants to live. She would like to treat her depression, but is concerned that others think she is crazy. Not only is she concerned about how people will react to her diagnosis of HIV, she is also concerned about the stigma of a mental illness.

Spiritually helps cope with HIV; she asks for guidance on her difficult journey.

Natalie lives for her young daughter; she gives her hope. Natalie had to make difficult

choices when she found out she was pregnant. Given that she has been on multiple medication regimens and had developed resistance, during her pregnancy she had to take a medication that could cause birth defects. She felt like she had to choose her health or the health of her baby. She stayed on the medication and fortunately her daughter was born healthy.

She has limited support due to practical issues; she does not have transportation and her family lives in other areas of the region. Her mother is still living; although Natalie has forgiven her, she is resentful that her mother would rather live on the west coast than close to her children. Concerned about stigma and discrimination, protects herself and is now isolated from friends. It seems that maintaining friendships without her friends knowing her status feels dishonest to Natalie. Rather than be betrayed, she shuts off from friends. Natalie is living alone with HIV, stating that there is really no one who understands her. She would like to be in a support group, but does not have transportation. Although she used to have a close relationship with a peer educator, he committed suicide recently. Natalie has tried to work with her new peer educator, but does not like him, as she felt like he was judging her.

Natalie has no clear picture of the future. Her untreated depression and isolation are interfering with her ability to plan for present and future. There is a sense of hopelessness as she contemplates her future.

Priscilla's Story

When we first met, Priscilla, a young woman in her mid-twenties, seemed to cling to her grandmother's belief that she was a strong woman. She appeared tough, ready to challenge anyone's perception of who she was as a woman living with HIV, articulating

that she did not care who knew her diagnosis. Yet, within her circle of family and friends, the diagnosis of HIV often provoked a strong negative response, leaving her deal with a disease that is frequently viewed as life or death. The siblings, whom Priscilla raised while a teenager and who stood by her side prior to being diagnosed with HIV, have since instigated episodes of physical and emotional abuse upon learning her diagnosis, with one brother stating that he would urinate on her grave. With such discrimination that has occurred in her family, Priscilla may be unable to cope with the possibility of betrayal from the community.

Repeatedly raped and abused by her mother's drug partners and her foster parents, Priscilla grew up in an environment that betrayed the fundamental innocence and safety of a child. She subsequently became pregnant with her foster father's child at the young age of 11. Priscilla did not raise this child, as she was only a pre-teen. As a young adult, Priscilla became involved with an older man, and became addicted to drugs. She prostituted herself to support her and her boyfriend's habit. Although Priscilla describes episodes of her boyfriend walking the streets to make sure she was safe, while she was prostituting for money for their habits, he was physically abusive to the extent that she could not negotiate safe sex. Subsequently, she was diagnosed with HIV, articulating that had she had a voice to negotiate safe sex, she may not be HIV-positive today. Thus has been betrayed by her sexual partner.

Currently, Priscilla is homeless, living day-to-day between a cousin's home and her baby daddy's home. Her life is chaotic, fragmented, and filled with uncertainty. She is pregnant with her fifth child, the only child who may not yet be put into DFS. Every other child has been taken away from her, a continual reminder that she may not be a

good mother. Priscilla seems to desperately want this child; it may be a hope for her future, or simply someone who she can unconditionally love and who will unconditionally love her, something that has been withheld from her in her young life. Drawing upon her religion and support from the Church, Priscilla, wants to create a safe place for herself, devoid of stigma and discrimination that seem pervasive in her life. Priscilla is not able to articulate her future; her focus is on developing stability in the present. With all of the barriers to achieving her goal, it is apparent that the future is not important to Priscilla.

Reandra's Story

Reandra, a young woman, was diagnosed with HIV while homeless, living in a hotel with her drug addicted boyfriend. Not feeling well and listening to friends' concern that her boyfriend was HIV+, she was tested. Her test revealed that she was HIV-positive. Her boyfriend was nonchalant. Low self-worth, stemming from her HIV status prompted Reandra to initially stay in the relationship. Once she realized that his passivity would kill them both, she broke away. She stated that "if you do not claim it, then you cannot take care of yourself". Although betrayed by her sexual partner, he is the father of one her children, thus she has forgiven him, despite the anger.

Reandra seems defeated by HIV, living a life with little meaning. Reandra was once a very active person, with a job and a "life". She now shields herself from the external world, staying at home most of the time. With a lack of transportation, her isolation is not entirely self-inflicted. She has difficulty maintaining regular healthcare appointments and is unable to attend women's support groups. A pervasive depression, that is currently untreated, prevents her from being more active. She seems to be passive in caring her

herself, not discussing her depression with the healthcare team and seemingly disinterested in counseling, a theme that is common amongst the group of participants. With a boyfriend who thinks a cure is being withheld and few friends, Reandra is living alone with HIV disease.

Prior to being diagnosed with HIV, Reandra was not a spiritual or religious person; since, she prays more often and reads the bible, stating that they both help her emotionally. She tries to care for herself physically by taking her medications regularly, eating a healthy diet, and would like to exercise. But finds that the depression has decreased her energy level and she cannot get a routine initiated.

When Reandra thinks about her future, she is inspired by her children. But there is a lot of uncertainty, particularly for her children if she becomes sick. Her son's father is HIV+ and is not currently in treatment. If she dies and her mother is not around, she is not sure who will raise her children. She sees her children as hope for her future, but at the same time there is anguish in leaving them.